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ABSTRACT

This document presents the proceedings of the National Disability Statistics and Policy Forum. Preliminary material includes an introduction (Mitchell P. LaPlante) and highlights of each presentation. Presentations are then grouped by session. Session titles and presenters were: (1) "Trends in Disability Prevalence" (Mitch LaPlante, Vicki Freedman, Gene Lowrimore, and Tony Young); (2) "Significance of Trends"(Lois M. Verbrugge, Jacob Feldman, and James Perrin); (3) "The Role of Trend Monitoring: Public Health and Social Perspectives" (Don Lollar, Glenn Fujiura, John Hough, Janet Guerrero, and Jane West); and (4) "Building Better Tools for Disability Trend Monitoring" (David Moriarty, Gale Whiteneck, Jamal Mazrui, and Mary Grace Kovar). Highlights of discussions following presentations in each session are also included. The keynote speech by Katherine D. Seelman, Director of the National Institute on Disability and Rehabilitation Research, focuses on the application of "the new paradigm of disability" to the research agenda. A summary of the conference and a list of participants completes the document. (DB)

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FORUM 4

Disability Forum Report

Trends in Disability Prevalence and Their Causes: Proceedings of the Fourth National Disability Statistics and Policy Forum

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Trends in Disability Prevalence and Their Causes

Proceedings of the Fourth
National Disability Statistics and Policy Forum

May 16, 1997
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INTRODUCTION

MITCHELL P. LaPLANTE
Director, Disability Statistics Center
University of California, San Francisco

Changes in the national prevalence rate of disability have important implications for society, affecting the need or demand for services, income transfers, determination of a standard retirement age, and the capacity of the population for independent living.

Conceptually, changes in the prevalence rate of disability signify at least one of the following: the frequency with which disability occurs to individuals is changing or the duration of the disability is changing. Changing prevalence may signify a change in the incidence of disability caused by physiological impairments, such as heart disease. It may also signify that people with heart disease are recovering from disability or living longer with a disability due to that condition.

Changes in the prevalence of disability due to a condition are different from changes in the prevalence of the condition itself. Disability has to do with human function, from the simplest actions to the most complex activities, and is an outcome not only of impairments but also the social and physical environments of individuals. For example, rates of disability for serious behavioral disorders may change because society becomes more tolerant, permitting people with such conditions to function better. In this case, the disability rate will decline, even when there is absolutely no change in the prevalence of serious behavioral disorders.

It is worthwhile to study changes in the rate of disability in the population even if the causes of changes cannot be determined precisely. Once a change is found, there is a desire to understand it, identify its causes, and, if undesirable, to take action against it or, if desirable, to take credit for it.

The aim of this forum has been to present some research evidence for changes in the prevalence of disability in our nation across all age groups, consider the implications as well as limitations of the evidence, and discuss potential causes.

As presented in this forum, the overall rate of disability has increased dramatically in the 1990s for children, adolescents, and young adults while the rate of disability in the elderly may have declined. In the age group 45-74, there is evidence of a substantial decline in disability from heart conditions, but back impairments and other conditions have increased. A central question is to what extent these changes are determined by physiological changes (Are certain impairments becoming more disabling?) versus environmental changes (Are certain features of the environment becoming less enabling?). Does better case ascertainment explain the increase in disabling asthma in children and adolescents, or is there a real expansion of the incidence of asthma? Do declines in the rate that older individuals need personal assistance in performing Instrumental Activities of Daily Living (IADLs) or even such basic functions as seeing and lifting indicate a change in physiology? To what extent are these trends influenced by changes in physical and social accommodations and social expectations, particularly in light of the passage of the Americans with Disabilities Act in 1990?

The provocative discussion of these questions that occurred at the forum is presented in these Proceedings. But the reader will see that there are no definitive answers for why these changes have occurred. One of the outcomes of this forum is the clear recognition that data collection and surveillance efforts must be given priority to ensure we collect appropriate data to answer these questions. More data collection is needed before research can provide the answers. Creative analyses of existing data, including surveys like the NHIS and SIPP, are always welcome but are limited by design. Our most useful data systems seldom measure environmental changes affecting disability, but in some cases environmental changes may be more important than changes in physiology. Data systems and research studies should be designed to test the influence of physiological and environmental changes affecting dis-

ability rates. Until then, changes in the prevalence of disability and disabling conditions in the national population can only be interpreted as to their putative causes.

Important changes have occurred in the rate of disability in our population, some good and some not, and we need to do a better job of understanding why.

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HIGHLIGHTS OF THE PRESENTATIONS

Mitchel P. LaPlante, Disability Statistics Center, University of California, San Francisco

- Among younger adults aged 18 to 44, 8.7 percent of men and 8.9 percent of women were limited in activity in 1990; this increased to 10.2 percent of men and 10.3 percent of women by 1994. This is more than a 16 percent increase in four years, and it shows a leveling off from 1993 to 1994. This increase translates to 3.1 million more 18- to 44-year-olds who were limited in 1994 compared to 1990. (p. 1)

- Among the 18- to 44-year-old group, we see an increase overall in the number of disabling conditions of 32.6 per thousand population.... In terms of discrete diagnoses, back impairments have increased the most, followed by disk disorders, nervous disorders, behavioral disorders, asthma, orthopedic impairments of upper and lower extremity, and carpal tunnel syndrome, which shows a very large increase in this age group of more than 1700 percent, or two disabling conditions per thousand. Psychoses, depression, and diabetes also increased. (p. 3)

Vicki Freedman, RAND Corporation

- Potential explanations for trends in disability include improvements in the underlying physiology of the elderly population, changes in expectations about roles, and changes in expectations about independence. The measures could also be sensitive to changes in living environments. In other words, it may not be that there really have been improvements in the ability to bathe oneself, but now more people have a walk-in shower, and it is therefore easier for them to bathe themselves independently. (p. 5)

- We see large declines in functional limitations among older Americans from 1984 to 1993. Improvements in seeing and lifting are not explained by changes in the socioeconomic or demographic composition of the older population. They don't appear to be explained by changes in survey design and coverage. And they are probably not affected by changes in expectations about roles and living environments. (p. 7)

Gene Lowrimore, Duke University

- Disability prevalence rates have declined about 14.5 percent from 1982 to 1994. That is the relative difference. If we take the 1982 age-specific rates and apply them to the 1994 population, they would project 1.2 million more people that would be disabled than we actually observe. This decline essentially occurs at all ages and all disability thresholds. There are 400,000 fewer people in institutions than the 1982 rates would actually predict.

  Among people living in the community, we find an age-adjusted decline in the proportion with only IADL limitation of 23 percent. (p. 8)

Tony Young, United Cerebral Palsy Association

- If we really do discover a trend that would have people who have disabilities with fewer functional limitations the impact on policy will be profound. If you start at the top with long-term services policy, it means we need to change our entire structure of how we do long-term services. It means a lot less high-cost institutional care, high-cost congregate care, and a much greater need for home- and community-based services, particularly personal assistance services. (p. 9)

Lois M. Verbrugge, University of Michigan and Westat, Inc.

- Like mortality, disability is a large-scale phenomenon in a population. Such big things about a population tend to be slow to change. And they are not easy to explain; they always have multiple causes that go back far in time. Only in a situation of catastrophic change in causes and predictors will disability or mortality rates change swiftly. Thus, in more typical circumstances, a short time span for a data set is unlikely to give you the story you are really aiming for. (p. 12)

- Key reasons for trends include changes in sociodemographic features of the population, in adaptive strategies, and in the nature and momentum of morbidity. Some of the causes are "far back" in the causal chain (such as behavioral risks of disease), while others are "close" (such as use of special equipment or personal assistance). Learning their importance helps public health officials plan an array of primary and secondary prevention programs aimed to reduce disability. (p. 12)

Jacob Feldman, National Center for Health Statistics

- It seems likely that there were changes of definition in the medical community that did, in fact, lead to diagnoses that had not been previously made, particularly in the case of asthma. It seems quite likely that the availability of inhalants made it a condition that was worth noting by the physicians. A physician who has something he can do about a condition is somewhat more likely to diagnose it and somewhat more likely to communicate it to the patient.

  This is an issue of artifact. Has the physiological prevalence of asthma gone up, or is the upward trend in the Health Interview Survey an artifact? (p. 14)

- It again seems possible that a lot of the improvement that we have in disability is really due to improved ability to cope with a given physiological situation, rather than any change in the prevalence of the physiological situation. There is no doubt about the fact that depression is now being treated in the elderly. A depressed person is probably less able to cope with a particular physiological impairment than is one who is in a better mood and who is more upbeat. (p. 15)

James Perrin, Massachusetts General Hospital, Harvard Medical School

- There is a large number of diseases for which there have been dramatic improvements in health care over the last two or three decades. The result is that 95 percent of children with severe chronic health conditions and disabilities currently survive to at least age 20. Very few children die. That is a real improvement over where we were when I started out as a pediatrician. These tremendous improvements in survival account for some of the growth in the rates of disability in this population. (p. 16)

- We have no adequate data systems whatsoever for monitoring child and adolescent disability in America. They simply don't exist. The sample just isn't large enough to be able to document most of the children's disabilities that we are interested in. You can only look at the large players in this—ADHD, asthma, maybe depression. Even those are difficult to monitor well in the NHIS. (p. 18)

Don Lollar, Centers for Disease Control and Prevention

- One of our research programs demonstrated that intervention can make a difference. They developed a wellness curriculum, which they piloted, and, over a six-month period, saw a 37 percent decrease in secondary conditions and a 43 percent decrease in physician visits among those who had been through the program. It is a small program, but it is a beginning in trying to focus on what we can do about health promotion and the prevention of secondary conditions. (p. 21)

- We have to see the disability community as including all of us, those with disabilities and those of us who are temporarily able-bodied. I think we have to celebrate our similarities rather than focusing on our differences. That means that the health community has to be much more sensitive to issues of transportation and housing and economics, but that folks in

those areas can't assume that we can do all of those things without being healthy. One of the things that we have to deal with, in terms of science, is to forge a close relationship between the several communities that are part of the larger disability community. (p. 22)

Glenn Fujiura, University of Illinois at Chicago

- We have seen dramatic changes in our cities over the past few decades, in terms of the economy, the population, the nature of health risks, and the resiliency of people exposed to these health risks. In particular, we have seen the dissolution of family structure in the city. The essential question here is this: Is the universe of disability changing because of these changes? (p. 23)

- The notion of social and economic factors is an old one. However, social and economic factors have always been treated as a background variable, as a contextual variable, one that is controlled or held as backdrop to more pointed analyses. This is ironic in many ways, because we are so intensely aware of these larger social issues in all of our research that they are almost ubiquitous in our research reports. Yet they are rarely the principal object of study in their own right. (p. 24)

John Hough, Centers for Disease Control and Prevention

- Data from the National Health Interview Survey show that hospital discharges for asthma have remained nearly constant during a 14-year period, while prevalence has increased by nearly three-quarters. According to the 1994 National Health Interview Survey, there were an estimated 14,562,000 cases nationwide. The estimated prevalence among all ages was 56.1 cases per thousand persons, but among children under 18, the rate was 69.1 cases per thousand. (p. 25)

Janet Guerrero, Centers for Disease Control and Prevention

- Injuries to the head and neck constitute 14.6 to 17.6 percent of firearm injuries, rising consistently over the three years of the study. In a firearm injury to the head, either the bullet will graze the head and the person is not likely to have a disability or it will penetrate the skull and cause a traumatic brain injury. The consequences of traumatic brain injury can be far reaching. It can lead to changes in executive functioning, such as initiation of new tasks, planning and execution, and speech and/or language production and comprehension, known as "aphasia." (p. 26)

Jane West, Jane West and Associates

- One question to ask is this: Have we seen data influence policy more in the disability area? An example that comes to my mind is the formula funding in the Individuals with Disabilities Education Act, which just passed. The law shifts funding from child count to formula funding over time, and that formula is weighted for poverty. I think that is in reflection of the acknowledgment of the long-standing association we have known between poverty and disability. (p. 28)

David Moriarty, Centers for Disease Control and Prevention

- What especially struck us, from all of our analyses to date, are the extraordinary differences based on the level of reported activity limitation. The group reporting no activity limitation also reports a very low mean number of recent days of bad physical health (1.7 days), 2.4 bad mental health days, and 0.8 activity limitation days. But those numbers go up dramatically as the degree of limitation reported increases. It goes up in physical health from 1.7 to 19.9 mean days; mental from 2.4 to 9.3; activity limitation of 0.8 to 16.9. There are similar patterns with pain, depression, anxiety, sleeplessness, and vitality. It makes a very strong case for the problems of secondary conditions relative to disability. (p. 32)

Gale Whiteneck, Craig Hospital

- The goal of disability surveillance is thought of as the use of the science of epidemiology to better understand the incidence, prevalence, and

impact of disability. It is often characterized by ongoing population-based surveys that identify the problems, needs, outcomes, and resource utilization of people with disabilities.

Although the Denver group felt that the ultimate goal of disability surveillance was to help improve the lives of people with disabilities in a wide variety of ways, there was also a clear recognition that the method of improving lives will be primarily indirect, through the use of data by other entities, as opposed to direct intervention. (p. 33)

Jamal Mazrui, National Council on Disability

- I believe it is very important for people with disabilities to be consulted in the design of research. I have worked with a university and have been a graduate student, and so I think I have some sense of that environment, and I think there is a tendency for researchers to feel that they know what needs should be studied and what questions need to be asked. They feel that is a matter of scientific inquiry, and there wouldn't be much that a lay person would contribute to that endeavor.

  But the reality is this: As economists teach us, resources are scarce, including resources to do research. So why not focus research on things that will be most helpful to people, given that you have limited money and staff to do research? (p. 35)

Mary Grace Kovar, National Opinion Research Center

- I want to talk about self-reporting of disability. I don't know anybody who knows more about what a person can do than the person himself or herself. It is no good asking my family physician, or whomever, whether I can do certain things. He doesn't know. I do. Furthermore, where do you think medical histories come from? They come from the doctor asking questions and people answering them. That is where we get our information. People know about themselves.

  What we cannot answer well is the kind of so-called objective measures that people keep putting on surveys: What was the date of your last doctor visit? How many doctor visits have you had in the last 12 months? How long were you in the hospital the last time you were in the hospital? (p. 38)

Katherine D. Seelman, National Institute on Disability and Rehabilitation Research

- There is no doubt that the new paradigm would be based on science, in terms of authority, but based on the disability community, in terms of legitimacy. I challenge all of us to really think about what that agenda is. The advocates have done their work. It is time for the research community to do more there.

  It seems to me, from the standpoint of the new paradigm, that we have to bridge the individual as a unit of analysis. Most of you deal with that unit of analysis in your studies, as well as social entities and the environment. Collaboration, the bridge between health and the health professions and engineering professions, is something we need more of. (p. 41)

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SESSION 1: TRENDS IN DISABILITY PREVALENCE

MITCH LaPLANTE
Director, Disability Statistics Center
University of California, San Francisco

I would define a trend as any directionally consistent and statistically significant change in the prevalence of disability over a period of several years. For example, an increase or decrease that can be described by a line or curve fitted to the data.

I am using the National Health Interview Survey, which is a national household survey begun in 1957 and which produces annual data up to the present. It includes several measures on disability, impairments, and illnesses and benefits from having a large sample size. The definition of disability is this: A person has a disability if he or she has an inability or a limitation in the amount or kind of major activity that he or she can do or is limited in any other activities in any way. "Major activities" include roles common to various age groups—school, work, and self care. "Other activities" include social, community, and leisure activities.

We see disability growth over the period 1970 to 1994. In 1970, 11.7 percent of the population experienced activity limitation. The rate rose gradually over the decade to 14.4 percent in 1981.

There was a change in the survey questionnaire introduced in 1982 that had a large impact on women and the elderly, mainly for the better, because it eliminated some of the gender and age bias in the disability questions. This questionnaire has remained in effect up until 1996.

During the 1980s, the rate remained around 14 percent, but increased from 1990 to 1994. This is a very significant recent increase. The long-term increase is largely due to population aging. We can see this when we age adjust the data: The trend becomes even more flat, with the lines for men and women coming closer together, because age-adjusting takes into account the greater longevity of women.

The more recent short-term trend is concentrated in younger age groups. When we look at ages over 45, it is very hard to see any growth. Essentially, the disability rate has remained constant for people 65 and above and for people aged 45 to 64. There can be some differences between various years, but what I am talking about is whether there is any real, consistent trend that we can see, and there doesn't appear to be.

Among younger adults aged 18 to 44, 8.7 percent of men and 8.9 percent of women were limited in activity in 1990; this increased to 10.2 percent of men and 10.3 percent of women by 1994. This is more than a 16 percent increase in four years, and it shows a leveling off from 1993 to 1994. This increase translates to 3.1 million more 18- to 44-year-olds who were limited in 1994 compared to 1990.

If we compare this to the Social Security Administration's experience with the Disability Insurance and Supplemental Security Income Program, those roles grew by 1.7 million. So we are seeing a much larger population increase in disability than Social Security has seen in their programs.

We also see substantial growth in children. Among those under 18, the rate of limitation increased for boys from 5.6 percent in 1990 to 7.9 percent in 1994. This is a 40 percent increase. For girls, the rate increased from 4.2 percent to 5.6 percent, a 33 percent increase. This translates to 1.5 million more children limited in 1994 than in 1990. In comparison, Social Security's rolls grew by about 0.6 million children. So, again, we see a larger population increase in disability among children.

When we look at personal care limitation, the proportion of the population needing assistance from another person in Activities of Daily Living (ADLs) or Instrumental Activities of Daily Living (IADLs) shows no really evident trend for the elderly population. When we look at 18- to 64-year-olds, there is an increase beginning in 1990 from 2 percent to 2.7 percent. And for children, we see an increase from 0.3 percent to 0.5 percent. These are significant increases, and it does show that the short-term increase since 1990 is to some extent also associated with growth in severe disability, as measured in terms of needing assistance in personal care.

In summary, we see that disability in the population under 45 has been increasing and disability in the population 45 and older is approximately holding steady.

This raises the question: Are there any conditions that might be associated with the recent growth in disability that we have observed? Are there any epidemiological trends that might be influencing the disability trend?

I have looked at trends in activity-limiting conditions, by diagnosis. This is not synonymous with counting numbers of people. On average, people limited in activity mentioned 1.6 conditions as causing their limitation. What I am looking at is the number of disabling conditions divided by the population to get a rate. The condition coding has not changed during this period. So I think this comparison is valid.

I am employing a classification that I used in the report *Disability in the United States: Prevalence and Causes, 1992*. The classification breaks down the disabling conditions into 173 discrete categories of conditions and also organizes them according to the ICD, to 18 chapters and 25 subchapters. This was done to get as much detail about disabling conditions as we possibly could from the 1992 survey, and I have taken this classification approach and applied it to each year, 1983 to 1994.

To see if there is a trend, I use what we call weighted least squares regression, with a curvilinear or quadratic fit. Because the increase in disability is evident at the later point in the time series, it is not quite realistic to assume that a simple line would describe the data.

We assess whether the fitted curve is better than a flat line—that is, one that has a slope of zero—using a chi-square test that takes into account the sampling errors. All the sampling errors have been computed using SUDAAN (Software for the Statistical Analysis of Correlated Data), which is appropriate for the complex design of the survey.

We test whether the chi-square for the flat line minus the chi-square for the fit is large. If so, then the trend is statistically significant; I am only reporting significance at the level of 0.01, which is very sound in statistical significance. I also use graphical inspection, just to make sure that things are as they seem.

I also compute the change in rate using the fitted values for the endpoints of the series. This helps to avoid any outliers that might give us a bigger impression of what a change is that has occurred. I report absolute change. Absolute change is more relevant to the issue of what is causing the disability rate to increase.

Relative change—that is, the percentage change in the rate for a particular condition—tells us that the change is adjusted for the initial rate at which the condition began. This can vary, particularly for less prevalent conditions.

When we look at all ages, we see that the rate of disabling conditions has increased by 19.4 conditions per thousand population. This is an 8.4 percent increase, and a very statistically significant trend.

With regard to the chapters of the ICD, looking at all ages, we see that impairments are the leading cause of disability, increasing by 17.1 percent over the period. This is followed by circulatory conditions, and we see a decrease in circulatory conditions of 23 percent. We also see an increase in musculoskeletal conditions. It is interesting to note that circulatory conditions were the number two cause of disability in 1983, but by 1994 they have been eclipsed by musculoskeletal and have become the third ranked cause.

There is an increase in respiratory conditions and in mental disorders. In all, twelve chapters of the ICD have shown a statistically significant increase over this period.

What we see at all ages is that, if we rank the conditions by those that have changed the most, in absolute terms, we see a statistically significant increase in orthopedic impairments of the back or neck of 4.7 disabling conditions per thousand, followed by asthma and intervertebral disk disorders. Back problems are increasing. We see increases in orthopedic impairments of lower and upper extremity and shoulder, psychoses, diabetes, carpal tunnel syndrome, hyperkinetic syndrome of childhood or hyperkinesis, cancer, depression, mental retardation.

When we look at conditions that have declined the most, we see that heart disease ranks at the top, with a decline of 7.9 disabling heart conditions per thousand population. Classified within heart disease are hypertension, ischemic heart disease, angina, and other forms of heart disease, which have all gone down significantly. We also see a decline in arthritis, atherosclerosis, emphysema and cataracts.

When we look at relative change—that is, the percent change in the rate—we see a very different distribution. Carpal tunnel syndrome ranks at the top with a 932 percent increase. That is followed by affective psychoses, metabolic disorders, hyperkinesis, adjustment reaction, prostate cancer in men, depression, anxiety, osteoporosis, and absence of a body part.

When we look at the relative decliners, we see that deformities of the lower extremity has declined, as have hemorrhoids, atherosclerosis, varicose veins of the lower extremities, ulcers, rheumatic heart disease, kidney stones, absence or loss of breast, angina, phlebitis, nervousness, retinal disorders, dermatitis, cataracts, absence of lung or kidney, and hernia.

Among children, we see a significant increase in the number of disabling conditions of 20.7 conditions per thousand children a 33 percent increase. By chapter, we see no trend in impairments, but we do see an increase in respiratory conditions. And we see a very dramatic increase in mental disorders.

When we look at the discrete diagnoses, we see that asthma leads the list in absolute change, followed by what I call "behavioral disorders," namely, neurotic disorders and personality disorders. Next are hyperkinesis, mental retardation, epilepsy, psychoses, curvature of the spine or back, and deformity of lower extremity.

When we look at the percent change, we see that behavioral disorders and hyperkinesis lead the list with increases over 200 percent. Asthma shows a statistically significant increase that is quite steady and is an 85 percent increase over the period. For curvature of the back or spine, we see that the latter years are different from the earlier years; not precisely a curve, but there does seem to be a decline in this condition. These are the only two conditions that actually declined in children.

Among the 18- to 44-year-old group, we see an increase overall in the number of disabling conditions of 32.6 per thousand population.

By chapter, impairments have increased significantly, and there has been an increase in musculoskeletal conditions. There are nine other chapters that have increased significantly, and mental and nervous conditions and respiratory conditions are those that lead the field.

In terms of discrete diagnoses, back impairments have increased the most, followed by disk disorders, nervous disorders, behavioral disorders, asthma, orthopedic impairments of upper and lower extremity, and carpal tunnel syndrome, which shows a very large increase in this age group of over 1700 percent, or two disabling conditions per thousand. Psychoses, depression, and diabetes also increased.

Discrete conditions that have declined include deformities of lower extremities, curvature of the spine, circulatory disorders, nervousness, ulcers, phlebitis. These declines are much smaller than the increases for the other conditions we have seen.

Among adults aged 45 to 69, we see a significant decrease in disabling conditions of 30.4 per thousand.

By ICD chapter, there is a clear decline in circulatory conditions in this group, by 38.4 per thousand. We have a shift from circulatory conditions as the leading cause of disability among 45- to 69-year-olds to becoming the third-ranked cause by 1994, following impairments and musculoskeletal conditions.

Looking at discrete conditions, orthopedic impairments of the back and lower extremity have increased the most. Carpal tunnel syndrome has increased and has a relative change of 725 percent, which is less than in the 18 to 44 year old group. Psychoses, asthma, behavioral disorders, depression, absence of a body part, and metabolic disorders have increased.

Heart disease leads the list of declining conditions with a 32 percent decline. Within this category, we see declines in hypertensive heart disease, ischemic heart disease, angina, and other types of heart disease. We also see a decline in osteoarthritis, and a decline in emphysema of 37 percent. Other circulatory disorders have declined, as well as hernia and certain disorders of the eye.

At ages 70 to 84, there is no significant change in the rate of disabling conditions. When we look at it by chapter, we do see a decline in circulatory conditions in this age group of 26.7 per thousand persons, but this is really the highlight for this group. We also see a slight decline in digestive disorders and a decline in symptoms in this group, but these are the only three chapters that have declined in this age group.

Discrete conditions: We see increases in absence of a body part, cancer, orthopedic impairment of lower extremity, osteoporosis, asthma, and Alzheimer's. Prostate cancer has increased, as well as allergies and some injuries. The increase in prostate cancer is about 175 percent.

When we look at conditions that have declined in this age group, we see a decline in circulatory conditions, particularly heart disease, which leads the ranks and has declined 13 percent over this period. That includes angina, ischemic heart disease, hypertensive heart disease, as well as others. We also see a decline in arthrosis and in arterial diseases, hernia, visual impairments, deformity of lower extremity; nervousness, and the category called "senility without mention of psychosis." The fact that Alzheimer's is up and senility is down probably reflects a change in reporting.

Then, when we look at the 85 and older popu-

lation, we see no significant change in the rate of disabling conditions per thousand. The only chapter that declined among the elderly is symptoms, which went down 19.8 percent.

Looking at discrete conditions, there are only a few that have increased significantly: orthopedic impairments, retinal disorders, osteoporosis, Alzheimer's, hearing impairments (reported as unknown whether they affect one or both ears), cardiac dysrhythmias, absence of a body part, other psychoses, and asthma.

Those that have declined include, again, senility. Cataracts have declined significantly, by 40 percent. Atherosclerosis (diseases of the arteries) declined by 66 percent. We see a decline of 63 percent in hemiparesis, or partial paralysis of one side of the body. These are the only conditions that have declined in the elderly.

In summary, we can now see that disability has increased at ages under 45, primarily because of increased mental disorders, back impairments, and asthma. In addition, other less prevalent conditions, such as carpal tunnel syndrome, have shown a very dramatic growth.

Although the rate of disability hasn't changed among people 45 and older, we do see substantial changes in the conditions causing disability. At ages 45 to 84, there is a substantial decline in circulatory disorders, which is accompanied by a decline in emphysema. This decline may perhaps be an outcome of smoking cessation and changes in lifestyle.

We see that declines in disability from heart disease, a fatal condition, have been offset by increases in back impairments, which is a non-fatal condition. If this trend continues, I think we would expect that disability may fail to decline in future years, while chronic disease disability continues to decline. This is a theme that has been in the literature for quite some time, and I would like to point out that Lois Verbrugge has also observed this in years past with the Health Interview Survey. I think there is current evidence for this trend, as well.

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VICKI FREEDMAN
RAND Corporation

The question that we are trying to answer here is whether the number of older disabled persons in the United States has increased disproportionally in the wake of declines in old-age mortality. A number of people have asked this question and not all have come up with the same answer.

Ken Manton and his colleagues have found that disability has declined among the elderly during the 80s and 90s. Eileen Crimmins and her colleagues have also looked at this question, using a different source of data, and have concluded that it is unlikely that disability has changed much. That is, they don't find consistent evidence for a trend during this time period.

The Committee on National Statistics of the National Research Council held a workshop a few years ago to review preliminary evidence on trends in disability. Workshop participants concluded that disability had probably declined among the elderly. Evidence was strongest for declines in mild disability, reflected in measures of Instrumental Activities of Daily Living (IADL) rather than Activities of Daily Living (ADL).

What I want to point out is that all the studies to date have focused on ADLs (such as bathing, dressing, feeding, and those sorts of tasks) and IADLs (such as managing money, shopping, and answering the telephone). These are measures of "role or task disability." The workshop report also concluded that the reasons for these trends, if there are trends, were unclear, and that a variety of reasons could explain these trends.

Potential explanations for trends in disability include improvements in the underlying physiology of the elderly population, changes in expectations about roles, and changes in expectations about independence. The measures could also be sensitive to changes in living environments. In other words, it may not be that there really have been improvements in the ability to bathe oneself, but now more people have a walk-in shower, and it is therefore easier for them to bathe themselves independently.

It is also possible that compositional changes in the population—for example, improvements in education or changes in the racial and ethnic mix of the older population—might be driving trends in disability. Changes in the prevalence of the use of assistive devices could also be responsible for people's perceptions about their abilities. Finally, trends could be an artifact of survey design and coverage issues If the instrument used to measure disability changes over time or the sample changes over time, estimates of trends could be affected.

The goals of our study were twofold. First, to estimate trends. And second, to shed light on potential explanations for changes in disability. Our approach was a little different from prior studies. Rather than focusing on ADLs and IADLs, we chose to focus on trends in what we call functional limitations—difficulty with basic bodily functions, rather than basic activities. Examples of functional limitations are difficulty bending, stooping, grasping, reaching, lifting over one's head. These limitations involve less interface with the environment and are thus more proximate measures of underlying health.

We also minimized the influence of survey design changes by selecting a survey that hasn't changed much over time. A third step in our approach was to factor out compositional changes in the population. Finally, for one functional limitation, we were able to factor out the effect of changes in the use of assistive devices over time.

We set out to find a survey with information on functional limitations at successive cross sections and information on basic socioeconomic and demographic characteristics of the older population. We used the Survey of Income and Program Participation, which was designed to measure the economic situation of individuals and families over time. Each year since 1984, a household sample has been selected and followed for two years, with interviews occurring once every four months.

Older Americans are not the primary focus of the SIPP, and neither is disability, but in four of the nine years that are available for public use, there was a detailed topical module on health and disability administered at the third interview.

I am going to focus on results from the 1984 and 1993 panels. We also looked at two other data points in between—the 1990 and 1991 panels. I agree wholeheartedly with Mitch's point about trends actually consisting of more than two data points, but for the sake of simplicity we decided just to present the 1984 and 93 points here. In general, excluding the intervening points does not change our substantive conclusions about trends.

The sample sizes are approximately 13,000 in

each of the 1984 and 1993 panels. To ensure that our trends were not, in fact, due to artificial changes in the survey design, we evaluated several threats to the comparability of the SIPP panels, including non-response, item non-response, proxy response rates, changes in institutionalization, and changes in question wording.

Attrition by the third wave, which is the time of the topical module, was relatively comparable between 1984 and 1993. Item non-response increased slightly over time, but it was very low. Only 3 percent didn't answer the questions about functional limitations in 1984 and only 6 percent didn't answer in 1993. Proxy response rates remained almost identical, with about 63 percent answering for themselves, and spouses answering for another 30 percent in both years.

We are not able to look at changes in the rate of institutionalization using the SIPP, because the SIPP is a survey of the non-institutionalized population. But Ken Manton and others have shown that the size of the institutionalized population remained relatively constant during this time period or, if anything, declined a little, which would work against our finding declines in disability.

Finally, the wording of the functional limitation questions remained stable, with very minor exceptions that I will talk about.

There are eight functional limitation measures in the SIPP, but we focused on four that were asked consistently over time. The individuals were asked:

- Do you have any difficulty seeing the words and letters in ordinary newspaper print, even when wearing glasses or contact lenses, if you usually wear them?
- Do you have difficulty lifting and carrying something as heavy as ten pounds, such as a full bag of groceries?
- Do you have any difficulty walking for a quarter mile or about three city blocks?
- Do you have any difficulty walking up or climbing up a flight of stairs without resting?

In 1984, for the last three questions, there was a parenthetical instruction to the interviewer, which basically said, "If the reference person uses a special aid, ask about their ability to do the activity while using the aid." That parenthetical was omitted in the latter year. If this has any effect on our estimates at all, it would lead to lower estimates of difficulty in the earlier year than in the later year, and thus any decline that we estimate would be underestimated. That is, this change works against finding a decline in disability.

The compositional variables that we control for, or factor out of our analysis, include age, which we measured in five-year age groups; sex; marital status; race, which we measured as black, white, and other; ethnicity, which we measured as Hispanic and non-Hispanic; education; liquid asset ownership, which includes whether an individual owned a savings account, a CD, a money market, or an interest-bearing account. We chose to use this liquid asset variable as a dichotomous variable rather than as a continuous amount because of the high level of missing information on amounts of assets in the SIPP. Finally, we netted out the effects of regional shifts.

We used the following method to analyze the data: We pooled the 1984 and 1993 data together, and we estimated a series of logistic regression models. The first set had only year as a variable in the model, and the second set had year and controlled for compositional factors. Based on these sets of models, we calculated what I call "crude" rates and "adjusted" rates, where the adjusted rates net out the effects of changes in composition over time. We compare the crude trends with the adjusted trends to see the impact of compositional changes on our conclusions about trends. To test statistical significance, we adjusted the variance estimates in accordance with the complex sample design of the SIPP.

Let me begin with the crude trends for the population aged 50 and over. We found large and statistically significant declines in seeing, lifting, climbing, and walking from 1984 to 1993. The prevalence tends to be higher than Activities of Daily Living and other measures and consequently our changes are larger than some of the other studies I have mentioned.

Once we adjust for compositional change, we still find large and statistically significant declines in each of the four functional limitations. In fact, declines are larger for seeing and lifting and only slightly smaller for climbing and walking than they were before we netted out the effects of compositional change.

When we do an age-specific analysis, we find that, for seeing and lifting, compositional changes do not explain the decline or the improvements in functional limitations for any of the age groups. For walking and climbing, however, compositional changes do appear to explain improvements for the 50–64 group. For the 65–79 age group, once we take into account compositional changes, the decline in climbing is no longer statistically significant.

This analysis does not factor out device use. For one functional limitation—walking—we were

able to explore the relative importance of device use in explaining trends. The SIPP had a question in 1984 about mobility-related device use and, in 1993, they had two questions about mobility-related device use. In 1984, they asked: Does the reference person usually use an aid to get around, such as crutches, a cane, or a wheelchair? In 1993, they split this question into two, and asked: Does the respondent use any of the following aids to get around: a cane, crutches, or walker, or a wheelchair?

Our approach was to compare crude and adjusted trends for two different models. First, we looked at whether the individual had difficulty walking. Second, we looked at whether a person either said they had difficulty walking or reported device use. We re-estimated the models with this fifth outcome, walking *or* device use, in order to understand the relative importance of taking into account device use versus taking into account compositional changes in the population.

For the youngest group (50–64), compositional changes are driving declines in disability. The decline is reduced from 2.6 percentage points to 1.4 percentage points. When we take into account both compositional change and assistive device use, the decline in disability is only one percentage point, and it is not statistically significant.

For the oldest age group (80 and above), once we take into account both compositional changes and assistive device use, the improvement in the ability to walk is three percentage points, but is no longer statistically significant.

But, for the middle age group (65–79), once we take into account both compositional changes and changes in the use of assistive device over time, declines in difficulty in walking are still large and statistically significant.

To summarize, we see large declines in functional limitations among older Americans from 1984 to 1993. Improvements in seeing and lifting are not explained by changes in the socioeconomic or demographic composition of the older population. They don't appear to be explained by changes in survey design and coverage. And they are probably not affected by changes in expectations about roles and living environments.

Compositional changes do appear to explain improvements in climbing and walking for those aged 50 to 64 and in climbing for those aged 65 to 79. Together, compositional changes and device-use changes may explain improvements in walking for the 80 and older group.

But as to the remaining, unexplained decline, we feel that it likely reflects changes in the underlying physiological well-being of older Americans. An important next step in this analysis is to look at which disabling conditions have declined among the elderly and whether the level of disability within those disabling conditions has changed over time. Future research should also focus on further understanding of these explanations and on implications of these trends for the demand for health care among the older population.

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GENE LOWRIMORE
Duke University

Most of the numbers that I will show you this morning are the result of work done recently by Professors Ken Manton, Eric Stallard, and Larry Corder.

The National Long-Term Care Survey is a series of four related surveys that were conducted in 1982, 1984, 1989, and 1994. Its purpose is to try to get a handle on disability and the use that elderly people, both in the community and in institutions, make of long-term care services. We designed the National Long-Term Care Survey, and the interviewing is done by the Bureau of the Census.

We have really good information on the cost of care because each person in the National Long-Term Care Survey is linked by HCFA, using an identifying number available from the Medicare records, to all their Medicare billing records for the period from 1982 through 1995. We get the from- and to-dates for service, as well as the ICD codes and the actual treatment. We also get the date of death of anyone who dies.

We start from the Medicare List File, and each time we do a wave, we take an additional sample from the Medicare List File. We can trace very successfully the outcome of any one person, and we have overall response rates in the neighborhood of 95 percent.

We measure disability by Instrumental Activities of Daily Living (IADL) and Activities of Daily Living (ADL). We administer a short screen interview to this sample that is drawn from the Medicare files to determine their ability or inability to perform the various ADLs and IADLs. When we talk about performing these activities with or without help, "help" for us means assistance from either a person or equipment.

Once a person gets into the Long-Term Care Survey, he or she stays in the survey for all subsequent waves. Our sample sizes are fairly large, roughly 20,000 in each year, with 36,000 people contacted overall.

The findings from this first analysis are relatively simple. Disability prevalence rates have declined about 14.5 percent from 1982 to 1994. That is the relative difference. If we take the 1982 age-specific rates and apply them to the 1994 population, they would project 1.2 million more people that would be disabled than we actually observe. This decline essentially occurs at all ages and all disability thresholds. There are 400,000 fewer people in institutions than the 1982 rates would actually predict.

We have some age-specific 1982–1994 rates. The proportion non-disabled for ages 65–74 went up 2.6 percent, for instance. The biggest increase in the proportion non-disabled was among the very old. In the moderately disabled group—the ones who only had IADL impairment—the differences don't look very large but, if they were converted to percentages, they would actually be fairly substantial. For ADL disability, there are some fairly large differences. There is a decline of 4.7 percent for those over 85.

Among people living in the community, we find an age-adjusted decline in the proportion with only IADL limitation of 23 percent. The decline was only 9 percent for the ADL-impaired, but the overall rate for people in the community declined from 18.7 percent to 16.2, which is a minus 13.0 percent change.

Some other results: The use of personal assistance in combination with special equipment and modified housing has increased 7.2 percent among the disabled. But the use of personal assistance without equipment or housing modification has declined 32 percent. So there is a much greater use of special equipment or modified housing. This analysis compared the 1982 waves to the 1989 wave, but we expect these trends to continue to 1994.

Finally, a profile of the 1994 population: 81 percent are healthy non-impaired. Those who don't have ADL or IADL limitations but report limitation of physical function make up about 3 percent. We observe the same thing with cardiopulmonary problems: it is almost 4 percent. The ADL impaired group with cognitive limitations due to dementia and stroke is 1.6 percent of the total. The group with some ADLs and IADLs and musculoskeletal problems is at 2 percent. The very severe ADL and IADL impairment group is at 2.7, and 5.2 percent are in institutions.

REACTANT:
TONY YOUNG
United Cerebral Palsy Association

We have gotten a lot of information, some of it conflicting and all of it interesting. I am going to try to focus on a portion of that information that I found most profound, that involving functional limitations and the evidence that functional limitations are declining, or that some of the more significant disabilities aren't as impairing as they used to be.

When I was reading through these papers, first of all, it caused some cognitive dissonance, because I have always been thinking that disability rates are getting bigger. I have believed that for ten or fifteen years, and I have done all of my policy work based on more, bigger, and more expensive.

So as I read through a paper or two that said that rates may be declining, at least in some areas, part of my mind would go toward that, and then the rest of my mind would grab it and pull it back. We played tug of war for a while, until I finally decided that I would go look at the methodological section and figure out what is going on. After two minutes of my brain having flashbacks to the terror of my statistics classes, I went back to the discussion area where I felt a lot more comfortable.

It succeeded in jogging my mind enough to think about what might happen if we really do discover a trend that would have people who have disabilities with fewer functional limitations, even if we have more people having more kinds of disabilities. The impact on policy will be profound. If you start at the top with long-term services policy, it means we need to change our entire structure of how we do long-term services. It means a lot less high-cost institutional care, high-cost congregate care, and a much greater need for home- and community-based services, particularly personal assistance services.

If you look at the possibility of supporting more people in their communities and fewer people in congregate areas, then not only do you need more personal assistance, but you need more community-based transportation, more services like Meals on Wheels, and a lot more assistive technology, particularly mobility-related technology and environmental control technology. In other words, shifting the emphasis from health care needs to serving and helping needs. That would have a major impact on Medicare and Medicaid.

In the Medicare debate, they are talking about what to do with the home health benefit. Medicare program managers will tell you: Don't ever say "long-term services" or "long-term care" to a Medicare person. Their blood runs cold. They run. They look for weapons to hit you with. The expansion of the home-care service in Medicare and the transformation of it to more of a helper service than an acute-care service could be the profound next step that Medicare needs to take. But I didn't say that.

The Medicaid program, of course, has an entitlement to nursing homes, which I think we may have just discovered we don't really want. We know we don't want it. We don't need it. What we need is home- and community-based services instead.

I was thinking: Now, we have got these people with disabilities. There are more of them, but they are more functional. They are living in the community. They are getting around because they have got transportation. They have got assistive technology. They are bored. What are they going to do?

Well, at least some of them are going to want to stay at work. Why would they want to work? Well, because the longer you work the wealthier you are when you retire. The more you can put away in savings, the less you have to take out of your savings per year to survive. So, it makes sense. I mean, you are already bored—you might just as well keep on working.

What kind of changes to income support policy are we talking about? A transformation from income supports to wage supports to keeping people in the work force longer by doing things that keep them at work more. A year ago Congress passed a law that says that if you are over 65, you can earn a ton of money before you lose your cash assistance. In the year 2002, you will be able to keep working and earn up to $30,000 a year from 65 to 70, even if you are retired, and keep all your money. It is a great deal. There are no financial penalties for staying at work. As a matter of fact, there is a huge financial gain for staying at work.

I would think that the cohort between 55 and 65 on Disability Insurance would like to get in on that deal, instead of dropping completely out of the work force and living on DI. They could keep some of that money and keep on working too.

Of course, if you are 65 and retired, you have got a guarantee of health coverage, because you are

on Medicare. You have already got your advanced technology for work, because there are all kinds of things that people can use right now to stay at work and stay productive. You are going to retain the same job. For people with disabilities, the policy would change to make sure that people either remained in the job that they had before they became impaired, with an accommodation, or got a new job with retraining. The bottom line is that we have got people who stay in the work force a lot longer.

The impact on employment policy changes because you no longer have people falling out of the work force. You have more competition for jobs. You have a much higher demand for services that keep people at work or retrain people and put people back to work. You have higher use of essential job functions, job sharing, telecommuting, virtual offices, and advanced technology, and all of a sudden you have the emergence of a new type of employment specialist: the remain-at-work guru.

The demand for increasing technology grows, because you have all these people in the community—moving around, working, recreating, playing with their grandchildren. The industry that comes up with technological solutions all of a sudden has a huge new market. So now we have a challenge in developing a technology-transfer policy. What are we going to do with all that stuff that DOD and NASA and Commerce and Energy have invented that are looking for markets?

This could lead to greater independence, greater wealth, and greater satisfaction in life for a huge population of people. But there is a caveat here. If this is really happening, policy-makers need to know about it, and soon, because Medicare and Medicaid are on the agenda. Newt Gingrich said just the other day, "Now that we have balanced the budget, it is time to start looking at how to pay down the debt."

There will be significant restructuring of both programs. This information should be on the table as that restructuring is done. If we don't have that information, we are liable to repeat the mistakes of the past, and we'll have a well developed and expensive institutional care infrastructure with dependency-based income support, rather than health and technology programs serving people who want to live, work, and play in the community.

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SESSION 2: SIGNIFICANCE OF TRENDS

LOIS M. VERBRUGGE
University of Michigan and Westat, Inc.

There is very active scientific interest in the dynamics of disability. I would like to start off by mentioning three streams of interest, of which this forum represents one.

The first stream is to understand the dynamics of disability at individual levels. For example, what are typical trajectories that individuals follow as they recover from hip fracture? The data serving this topic are usually prospective longitudinal panel data, though retrospective longitudinal data can also be appropriate.

The second stream, which includes this forum, involves dynamics at a population level. What are the changes in the disability status of the population (usually defined by age and geographic area) as individuals exit and enter that population? The ideal data for understanding trends are either repeated cross-sections or a panel study that is replenished over time. The National Health Interview Survey is an example of the former, and the National Long-Term Care Survey (NLTCS) is an example of the latter.

The third stream is also at the population level. There is a great interest now in "synthesis indicators," which summarize the details of disability for a population by single indicators. An example is active life expectancy. Beyond that, even more synthetic in some sense, are indicators about compression and expansion of morbidity in a given society.

The purposes of all these analyses relate to public health, and very often to the public purse. In particular, I would like to indicate how the three papers in this session relate to those two sides of public interest.

The first question to ask about the rates presented is their descriptive quality, and the second is explanatory. First, are they good rates? Second, what precedes the rates or what succeeds them? If you are interested in what precedes the rates, you ask: What caused the dynamics seen in the population? Both Vicki's paper and Mitch's paper align with that spirit. On the other hand, if you are interested in what these rates portend for the future, whether the future is next year or several decades ahead, then you are interested in aggregate implications, often in dollar cost or numbers of persons. That is the main aim and spirit of much of the NLTCS trend analyses.

Several comments about trends:

1. Mitch's definition of a *trend* is important. The word is often overused. Something that happens between two time points is a change, not a trend. Comparative differences between groups at a single time is a differential, not a trend. The essence of a trend is a pattern over time, and that is Mitch's definition. When do dancing data points in fact show pattern and constitute a trend? This evaluation is not straightforward or simple; it requires a combination of judgment and statistics.

One should never statistically analyze a series of data points to find trends until one has looked at them visually. With Mitch's many plots of changes in rates of chronic disabling conditions, what I would have done is lay them all out on the floor and take a long look. Once statistics and your eyes have been the guides, you make statements about presence of trends and begin the job of explaining them or projecting their implication.

2. Most papers on trends and changes in disability in the U.S. population show small absolute changes. Although not a rare phenomenon, disability is a rather low-rate phenomenon in the population except at older ages. So changes over time are also small. That is why researchers often turn toward expressing the changes in terms of relative or percentage changes. There is a great attraction in doing so, of course, because you usually have got something bigger to talk about. Until recently, the pressure to show things in their big way, their relative way, often won out.

Now there is a much more balanced approach, and emphasis is placed on both absolute and relative results. (This same situation occurs when presenting differentials. One should always discuss both absolute changes and relative changes,

because the story can drift differently in both domains. Both views are true, but they can say somewhat different things.)

3. All surveys being used to look at trends in disability in the U.S. population suffer from a rather short time span, except for the National Health Interview Survey. Like mortality, disability is a large-scale phenomenon in a population. Such big things about a population tend to be slow to change. And they are not easy to explain; they always have multiple causes that go back far in time. Only in a situation of catastrophic change in causes and predictors will disability or mortality rates change swiftly. Thus, in more typical circumstances, a short time span for a data set is unlikely to give you the story you are really aiming for.

4. There is great merit in the work that is now being done on simulations of population health and disability profiles, and also on the theory of epidemiology of disability. The work being done by Luc Bonneux and Jan Barendregt in The Netherlands is beautiful stuff on the profiles of what happens (and probably will happen) to disability and morbidity rates when particular diseases are changed. Michael Wolfson's work on microsimulations also has that same spirit, as well as that of Jay Olshansky and colleagues. As a principle, researchers of disability trends should engage in large-scale thinking about population prospects, based on simulations and theory.

5. Lastly, I want to discuss feelings about trends. In public health, one usually wants rates of bad things to go down and good things to go up. Feelings about disability trends are always there, it is difficult to be neutral. Advocacy groups have a still more perplexing situation. When a rate goes up, it can inspire new advocacy momentum on behalf of their group. If that same rate were to go down, it would be cause for cheering, since it suggests a better status for the group. Still, virtually everybody (whether in science, public health, or advocacy) fundamentally wants disability rates to be low and diminish.

Now we will discuss explanations.

1. Several years ago, the National Council on Disability sponsored a conference in which one of the key issues was: How can survey research help us learn whether the ADA is working? Now, just a few years later, ADA is alive and well in the United States, and trends that are seen (the small trends in disability data) are swiftly attributed to its beneficial outcomes.

But trends and their reasons are not the same thing. To look at reasons for trends in disability is likely to be very challenging and very frustrating, because you dream up possible explanations only after the data stream is behind you. As a result, you have often missed the boat for measuring their course and relationships to disability. Missing the boat shouldn't stop an inventive scientist. Even if you get there too late, in some sense, cleverness and imagination can help out a good deal. Let me cite several of what I think are the most inventive analyses of trends in disability:

(a) Tom Chirikos's work on work disability trends in the United States is lovely. Also, John Bound and Tim Waidman have recently published an article using NHIS and several other data sources. Ed Yelin's work is an additional fine complement. (b) Dorly Deeg used completely different data sets from The Netherlands from the mid-1950s to early 1990s to look at relationships between chronic conditions and disability outcomes, in order to explore the relationship between morbidity and disability. (c) Vicki Freedman and colleague's article is a fine example of deftly using a data set to speak to a host of possible explanations, some having to do with morbidity and the pathway of disablement. (d) Lastly, the work done by Eileen Crimmins and her colleagues has been excellent and is represented well in the literature.

2. In explanatory research, the notions of artifact and bias often crop up. The word "artifact" comes from artifice. People who call something an artifact are really saying: "I think this factor may be in my indicator. But I wish it weren't." Wishing is nice, but the scientific endeavor really is aimed at measuring. If you can, rather than wish it away, you should bring the factor into the analysis and try to measure its impact on the indicator. In that sense, things that are called artifacts can be the foundation of scientific endeavor, rather than unpleasant intrusions. I think it is perilous to call things artifacts because it excludes them from further substantive purview. If something is embedded in the indicator, it is important first intellectually to admit that and then do your best to measure it if possible.

3. The roster of explanations is long. Key reasons for trends include changes in sociodemographic features of the population, in adaptive strategies, and in the nature and momentum of morbidity. Some of the causes are "far back" in the causal chain (such as behavioral risks of disease), while others are "close" (such as use of special equipment or personal assistance). Learning their importance helps public health officials plan an

array of primary and secondary prevention programs aimed to reduce disability.

In conclusion, there is no one path for disability trends in the United States. Eileen Crimmins and other colleagues have been emphasizing this recently. You cannot expect one path for the variety of indicators. What you hope is that you have good measurement and also good understanding about the genuinely diverse past. All the trends you heard about in this session are true. Now we must go about trying to understand how those different paths came about and coexist.

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JACOB FELDMAN
National Center for Health Statistics

I found some examples of trend data from the past. One such trend involves restricted activity days, in which a person either missed school or was in bed or was not able to do his or her normal activities. It may be due to an acute illness, rather than a chronic illness of the sort we are dealing with here.

Among poor children, there was an enormous increase in the number of restricted-activity days between 1964 and 1973. Presumably, things got much worse for children between 1964 and 1973, despite the fact that Medicaid came into being for poor children in 1966. School-loss days also went up. Due to the fact of Medicaid, apparently, somehow health got worse.

When we look at doctor visits, we find that, prior to Medicaid, practically a third of poor children under 17 had not seen a doctor for more than two years. Among the non-poor, there was a much higher rate of use. But with Medicaid, the average number of doctor visits per year went way up for poor children. Medicaid, neighborhood health centers, maternal and infant health programs—a whole variety of programs that were introduced or expanded during the Johnson Administration—are in fact responsible for these phenomena, both in terms of the increased incidence of reported illness and the increased use of medical care.

The same phenomenon occurred in the United Kingdom when the National Health Service was introduced. There was a survey of sickness in England at the time, and there was a great increase in reported illness among the poor. Obviously, what we are dealing with here is improved ascertainment and, in some cases, earlier diagnosis or greater awareness of illness; in fact, taking measures to address those illnesses.

We see the same phenomenon now. I have been working on uninsurance in children. If you look at the reported health status of children in the NHIS, you can see very clearly that uninsured children are reported as having very little illness, as well as very, very little use of medical care. Some of them really are healthy, but in other cases, there is clearly a very severe underascertainment going on.

Frank Corrigan mentioned the Government Performance and Results Act (GPRA), which takes performance measures and sets out performance goals for various government agencies. The success of agencies such as NIDRR could be measured in terms of a decrease in reported disability in surveys. That decrease is not necessarily a good thing. In fact, an increase might actually be much better. In other words, an increase might indicate that people are receiving care and are receiving rehabilitative services, which, in the long run, might greatly improve their quality of life. It is extremely risky to use various types of trend data to indicate failure.

Let us take the upturn in disability prevalence in the youngest age group. Ed Yelin implied that the trend that Mitch reported is again some indication of failure, when in fact it might very well be the best possible result, the result we would really like to have. While it is clearly not an issue of a real change in access to care that occurred during that period, there was a very large increase in the number of children covered by Medicaid. There were expansions of the Medicaid program that occurred during the latter part of the time that Mitch has studied, but this was basically a switch from private insurance to Medicaid, rather than an improvement in access.

However, it does seem very likely that there were changes of definition in the medical community that did, in fact, lead to diagnoses that had not been previously made, particularly in the case of asthma. It seems quite likely that the availability of inhalants made it a condition that was worth noting by the physicians. A physician who has something he can do about a condition is somewhat more likely to diagnose it and somewhat more likely to communicate it to the patient.

This is an issue of artifact. Has the physiological prevalence of asthma gone up, or is the upward trend in the Health Interview Survey an artifact? I think there is a condition that is now being treated that had not previously been treated, that, in fact, it might be benefiting the child very much. In the past, there were children who had chronic coughs that were not diagnosed and therefore were not treated; their prognosis was poor. I think we have to take the upward trend as a good sign. How we deal with that does become quite complex—every upturn in disability is not a positive event. However, I think we would need to look at it far more carefully, and there are data bases around that would permit that.

We were also supposed to talk about possible causes. Now that I have discussed the possibility that there is no actual upturn in the physiological

basis of disability, I would like to give a few examples of situations, or of analyses, that might throw some light on possible causes of an actual upturn if there were one.

There has certainly been a great improvement in survival of low birthweight infants during the period in question. Infant mortality rates have dropped substantially, primarily because of improvements in survival of children from 1,500 grams to 2,500 or 3,000 grams. That particular improvement could mean that the children who are at greater risk of illness are surviving, that some of these very low birthweight children who are saved may experience greater illness later in life. Certainly some of the learning disabilities that are very much at the core of that increase might be from the group that has been saved.

There are a number of analyses that could detect that. For instance, there is a Health Examination Survey (HANES 3), done in 1988–93. It has a great deal of information concerning the prevalence of learning disabilities and other types of disabilities among children. Those data are linked to birth certificates. We know whether this was a low birthweight child or whether it was a birth with complications, and we are able to look at the rate of disability in such children to see if that could account for part of it.

Another explanation that has been given for the increased disability is the increased use of day care during that period. There are data that would enable us to test whether infections and communicable diseases increase for children in day care. It is conceivable that damage from those illnesses have caused the increase in asthma.

There are other extensive data sets that will help throw light on the extent to which the trend is due to improved ascertainment versus increased susceptibility. There was the Maternal and Infant Health Survey that NCHS last did in 1988 and 1991, which takes a sample of birth certificates and collects information from the mother concerning details of the birth, as well as information on the first three years of life of these children. Again, I think this is a data base that would help indicate whether there is increased susceptibility.

One final point along the same lines: Let's say that the decrease in disability that was reported among the elderly does hold up in other surveys. If a number of studies show the same thing, that is probably the most important method of testing whether there is an artifact or a basis for the inference. It again seems possible that a lot of the improvement that we have in disability is really due to improved ability to cope with a given physiological situation, rather than any change in the prevalence of the physiological situation. There is no doubt about the fact that depression is now being treated in the elderly. A depressed person is probably less able to cope with a particular physiological impairment than is one who is in a better mood and who is more upbeat.

I think, as Vicki did point out, that we are really dealing with the impact on the individual's life rather than with the physiological situation. It seems extremely likely that the change in coping ability, either because of the improved educational distribution of the population or because of the psychotropic drugs or other types of treatment of emotional conditions, is responsible for any decline in disability rates, rather than any change in the physiological impairment itself.

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JAMES PERRIN
Massachusetts General Hospital, Harvard Medical School

I want to focus on four issues: (1) the differences between adult and childhood disabilities; (2) changing patterns, including trends, in childhood disability; (3) the relationship of these changes to changes in the Supplemental Security Income program for children and adolescents; and (4) the implications that I see for monitoring and data in the future.

First of all, let me focus on differences between childhood and adult disabilities. There are three major topics in that area: the differential epidemiology, the differential vulnerability, and the implications for manifestations of disability at different developmental phases of childhood and adolescence.

Differential epidemiology: There are few common chronic conditions in children, compared to adults. Adults face 8 to 12 very common chronic disabilities, compared to 4 or 5 conditions in childhood. Everything is rare to extremely rare, which has tremendously important implications for the kind of data that Mitch presented.

What are the common disabilities in children? Only asthma, attention deficit hyperactivity disorder and related conditions, mental retardation and developmental disabilities, recurrent otitis media, and depression. Even diabetes, cystic fibrosis, and sickle cell disease are conditions with a prevalence of about one in a thousand or less. The relative rarity creates real problems in the development of adequate data to understand changing patterns of disability for children.

Second is the issue of the dynamic relationship of disability among children with the environment in which they live, particularly their households and their schools. We have a great deal more understanding in the last decade of the plasticity of brain growth and development. We know so much more about the interaction of early childhood experiences and actual brain structure and function that we can no longer talk about children being born with something that is relatively static with respect to, for example, neurological development. And thus it becomes increasingly important to understand the relationship of early experiences and the prevention of secondary disability in many children.

The other point about the environment is that children remain the poorest segment of our society. It was interesting to hear Jacob Feldman talk about the 1964–73 experience and suggest that it was related to Medicaid, because in 1973 only about a third of children in poverty in America were covered under Medicaid. It was a rather remarkable phenomenon, and it is only in the last few years that more than 50 percent of American children who live in poverty have Medicaid. As he pointed out, the changes are likely related to a wide variety of public and private programs that occurred at that time, but certainly not very much depended on Medicaid.

The dynamic relationship of early childhood with the environment in which children live has tremendous implications for long-term disability, especially for the prevention of secondary disability.

My third point is that it is very difficult to measure disability in anyone, and particularly in children, because of the differential aspects of development. In other words, we probably don't care about toileting in a 6-month-old. Very few of them are capable of managing toileting activities. Yet we are quite concerned about a 6-year-old who is not capable of toileting appropriately. And you can go through a variety of other patterns there: asthma occurring in a 3-year-old is a fundamentally different condition from how it presents itself in the 15-year-old, and it is treated differently.

Finally, in that developmental aspect of life, how children respond to the onset of disability also varies substantially at different ages. A child born with a disability manages it quite differently from a child who develops a disability at age 18. The implication is that you can't simply assume that children's disability is a minor variation on adult disability.

A second area that I want to focus on reflects some of Mitch's data on changing patterns of childhood disability. If he had gone back to the 1960s and looked at the rates of limitation of activity of people under age 18, they would have been on the order of 2 percent, rather than the 5 or 6 percent range of today. This is a real, well documented trend, reflecting major improvements in survival. When I started out in pediatrics, most children with leukemia died. Very few survived.

There is a large number of diseases for which there have been dramatic improvements in health care over the last two or three decades. The result is that 95 percent of children with severe chronic health conditions and disabilities currently survive

to at least age 20. Very few children die. That is a real improvement over where we were when I started out as a pediatrician. These tremendous improvements in survival account for some of the growth in the rates of disability in this population.

A couple of other points: I disagree with a point that Jacob Feldman made. I think the data out of neonatal intensive care units would suggest that we are not increasing the rates of disability in the last two decades as a result of those changes. We have decreased the size at which babies survive, and we have markedly decreased the disability rate in larger babies. In other words, as an example, 20 years ago a child born at 1500 grams had a pretty good likelihood of mortality and also had a pretty good likelihood of surviving with substantial lung and central nervous system disease. Now, that child will survive with very little evidence of long-term morbidity.

At the same time, 20 years ago, a 600-gram baby would not survive, with very few exceptions. Nowadays that child will survive, again, with very high likelihood of pulmonary or central nervous system disease. But the attributable risk—not the relative risk—of these extremely low birthweight infants is so small that we are talking about very marginal changes in long-term disability.

There have been some other changes. We don't know much about the long-term outcome of children exposed to toxic substances in utero. We really don't have very good long-term data on crack babies. I can't tell you whether that is a significant contributor to long-term childhood disability, but I don't think it is. AIDS didn't exist 20 years ago. It still doesn't affect a large number of children, but rates are growing. The attributable risk of AIDS is relatively minor in the total population that Mitch reported.

The big players are asthma and attention deficit hyperactivity disorder (ADHD). Those two conditions are the big changes, and that seems to be consistent in a relatively wide number of studies. I don't think we have much more than speculation as to why there have been these dramatic increases.

We know that asthma has been increasing in prevalence over the last 15 years, at least. International data support the growth in asthma, at least in industrialized societies. There is less good evidence of growth in asthma in undeveloped or developing countries, but it is a pretty consistent pattern.

I don't agree that this is related to the onset and availability of inhaled medications. The upswing in asthma, according to Mitch, began in 1990. We had inhaled medications way before that, so I don't think that is a particularly good explanation, but I don't know if I have any better.

A number of years ago, we did some analyses of the Child Health Supplement of the NHIS looking at the change from 1981 to 1988. We also demonstrated a substantial increase that was greater among school-age children than very young children. And there was far more growth among Caucasian children than among African American children, although our study and other studies demonstrate that African American children have substantially higher rates of asthma than white children. I don't think we know why. Is there a change in the environment? Are there really more cockroaches in New York City than there used to be?

ADHD also shows a remarkable pattern. The rates of sales of Ritalin in this country have quadrupled since 1990 for children under age 18. I have no good explanation. Is it in the water? Is it in the environment? Is it some toxic environment? Is it that doctors have changed radically? A quadrupling in the prevalence of the condition makes no sense whatsoever, and we are trying to understand that phenomenon. It is a remarkable change.

I want to mention the growth in Supplemental Security Income. Most of you probably know that SSI for children has also almost quadrupled in size since about 1989. It has gone from about a $1 billion program to approximately $10 billion in cash and Medicaid expenditures during this time. This growth reflects some of the data that Mitch showed. One of the issues that received much bad press over the last two-and-a-half years has been the tremendous growth in the prevalence of the diagnosis of ADHD among children getting SSI benefits.

We have looked at some of our Medicaid data, supported by HCFA and the Maternal and Child Health Bureau. We have been able to show that there has been a 400 percent growth in the prevalence of Medicaid claims for ADHD among the SSI population, but we have also been able to show that, in our comparison non-SSI populations, there has also been almost a 400 percent growth. So I don't think this is an SSI problem, but rather reflects secular trends in the diagnosis of ADHD generally.

As Mitch said, there has been a 1.5 million increase in the number of children with substantial disability during the early 1990s. At the same time, SSI grew by about 600,000 recipients. Paul Newachek, looking at similar data to Mitch's some years ago, demonstrated that, prior to the 1989 and 1990 changes of SSI, children had about half the likelihood of receiving SSI benefits as adults with

the same degree of limitation of activity. That was one of the pieces of data used to support the Supreme Court's Zebley Decision in 1990 to make SSI more equitable for children. We still have not achieved equity and, even though the program will change shortly, I don't think the number of children receiving SSI benefits is going to decrease nearly as much as some people think, including the Administration.

My fourth and final topic: What does this all mean for monitoring and for data in the future? The simple response is to say: We have no adequate data systems whatsoever for monitoring child and adolescent disability in America. They simply don't exist. One of the reasons that Mitch was able to show far fewer significant trends for children than adults is that the sample just isn't large enough to be able to document most of the children's disabilities that we are interested in. You can only look at the large players in this—ADHD, asthma, maybe depression. Even those are difficult to monitor well in the NHIS.

As an example, if you had a sample size of 20,000, about a fifth of what Mitch talked about, you might have in that sample about 6,000 or 7,000 people under the age of 18. Of that group, maybe 600 or 700 would have any chronic condition. About 350 or 400 would have activity limitation. About 200 would have severe disabilities, and at least one-third of those would have mental retardation or developmental disabilities. Another one-sixth would have severe asthma, leaving the remaining half for everything else. You have perhaps one child with diabetes, one child with cystic fibrosis, no children with leukemia, one child with hemophilia, and so on. You can't study trends for a sample of one.

The new National Health Interview Survey on Disability does, fortunately, have vastly more data, but it is unfortunately a one-point-in-time study. It provides no information about trends over time. The new Medical Expenditure Panel Survey has a sample size too small to be able to study disability in children effectively.

So, my final word: If we going to understand disability in children and adolescents, we must first develop adequate data systems with which to do it. Mitch has done more with current data than anyone else has thought possible with NHIS. But his work demonstrates the limitations of this data set. We continue to deal with black boxes in trying to understand who these children are and what are their patterns over time.

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GENERAL DISCUSSION

Bob Griss, Center on Disability and Health:

I am somewhat frustrated by the focus on trends in the abstract. With the exception of the last speaker, the discussion of trends has not been focused on particular policy issues or problems that we are facing as a society.

The list of possible causes for changes in disability rates has been identified. It could be lifestyle. It could be environmental changes. It could be physiological changes. It could be the success of the health care system. It could be lots of possible things. But I am getting the sense that the type of data that we really need doesn't exist. The policy implications of changes in disability or health status are not clear. I am really sensing that we don't know what causes what, and so we don't have intervention strategies.

We hear from the methodologists in the health care system that the small numbers problem makes it very difficult to find out whether people with disabilities are getting appropriate health care, based on outcomes. Are there ways of aggregating the experience for people with different chronic health conditions, so that we can get an aggregate measure that is free of the statistical reliability problem and that will give us a club with which to hold health plans accountable for the way people with any number of disabilities have changes in their health status?

Lois Verbrugge:

There is so much that can be done with existing data. There are a number of data sets that exist that have not been tapped in imaginative ways.

That means greater leaps of inference from the findings, but there is nothing wrong with inference. In other words, public health programs may need to have some of their pushes and shoves come from something that is less than the dream.

Mary Grace Kovar, National Opinion Research Center:

I don't think the increase in asthma is strictly ascertainment, because we have so much other data. For example, the Hospital Discharge Survey shows the same kind of increase.

Jacob Feldman:

It is a very slight increase, meaning that it has been ascertained, and therefore it gets treated. The point I was trying to make is that there is a great deal of under-ascertainment, that there is a great deal of undiagnosed illness that does not get treated. The recognition of that illness can lead to treatment, which is highly desirable to have.

James Perrin:

We have been looking at hospitalization in a few cities—Boston, New Haven, and Rochester. It is curious that hospitalization rates, both nationally and in these three communities, are decreasing substantially for children in general. That is not true for asthma. There has actually been a continuing increase in the rate of hospitalization for asthma in those three cities.

One of the interesting clinical findings from those studies is that one of the reasons for the increase, which is greater in Boston than in New Haven or Rochester, is that the quality of primary care, as measured by access to ongoing preventive services, is substantially lower in Boston than it is in New Haven and Rochester. Therefore, children are probably not getting appropriate and adequate care in Boston, which accounts for the continuing rise in hospitalization there.

Jack Guralnick, National Institute on Aging:

I would like to raise the issue of attributing specific chronic conditions to disability. In young and middle-age populations, we frequently have a situation in which the individual has one condition, and it is a pretty obvious cause and effect. In older populations, of course, we have a lot of comorbidity.

In a study that my group at NIA is doing with Linda Fried and her colleagues at Johns Hopkins looking at disability in older women, we sat down with a group of geriatricians and various medical specialists and looked at the results of a three-hour interview, which was mainly focused on disability, and laid out all of the participants' medical charts and fought for two hours about the underlying diseases causing disability. After going through about 20 people's records, we threw up our hands and said: "We can't decide on the diseases causing disability."

That is a complicated approach to something that could be simpler, but how valid are these kinds of self-reported issues of the disease responsible for disability? Will we ever be able to sort any of this out?

Mitch LaPlante:

This is a key issue in the work that I am doing with the Health Interview Survey. I have used people's attributions of disability as reported in the survey. Somebody could, for example, have heart disease, orthopedic impairment, and diabetes. They are asked simply whether they are limited in any activities, and then they were asked, "What condition causes this limitation?" People may say that they have a limitation from an orthopedic impairment and diabetes, and they may not consider the heart disease to be a condition that limits their activity.

I can only go by what respondents tell us. The survey does ask people if they have multiple conditions that cause them to be limited and which one is the main condition.

As I reported in *Disability in the United States: Prevalence and Causes, 1992,* people do tend to ascribe their main cause of disability to disabling conditions that are more severe. That attribution itself may be considered an indicator of more severe disability. But it doesn't always work that way. For example, if two people were to have mobility impairments due to diabetes, one person may focus on the mobility impairment as the cause of disability, while another person who better understands the etiology might say that diabetes is the main condition that causes the disability.

These are all things that need to be studied. In general, I think I have done more with looking at the analysis of chronic conditions in the Health Interview Survey than others who may doubt the reliability of self-reported data. I have done this under the assumption that people with disabilities know more about their conditions than people without disabilities. And many of the medical record check studies have not looked at that part of it. Medical records under-report impairments, and I think that we haven't really done the research to look at how well people with disabilities report their conditions in total or in terms of co-morbidity.

I know that the Disability Examination Study that Social Security is considering may offer some insight into this, and I would encourage that effort to look at the issue of how conditions are being reported. As to whether we can solve co-morbidity and the attribution of disability to particular conditions, if you and Linda Fried can't do it in the Women's Disability Study, that is an indication that it is very difficult, if not impossible, to do.

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SESSION 3: THE ROLE OF TREND MONITORING: PUBLIC HEALTH AND SOCIAL PERSPECTIVES

DON LOLLAR
Office on Disability and Health, Centers for Disease Control and Prevention

In 1988, the National Council on Disability prodded the Congress to appropriate money for disability prevention. At that point, there were two emphases: One was on the primary prevention of disability and the other was on secondary conditions. At CDC, the emphasis was originally placed on primary prevention, focusing on three programs that related to injury, chronic disease, and birth defects and developmental disabilities. The funds were distributed to the states, so that much of the money was spent on state-based programming.

The injury program and the chronic disease program, both formerly parts of our Center, have now become Centers to themselves, with significantly larger budgets and emphases on primary prevention. The birth defects and developmental disabilities division is still in our Center; it has also grown exponentially.

As this growth happened, we realized that the Disability Prevention Program was losing a sense of identity. We began to look more clearly at the secondary conditions issue; that is, focusing on the health of people who already have disabilities or are identified as having disabilities. Our program is going to focus on public health as it relates to the prevention of secondary conditions among people with disabilities, and health promotion in that population.

One of our research programs—work done by Tom Seekins at the University of Montana and Glenn White at the University of Kansas—demonstrated that intervention can make a difference. They developed a wellness curriculum, which they piloted, and, over a six-month period, saw a 37 percent decrease in secondary conditions and a 43 percent decrease in physician visits among those who had been through the program. It is a small program, but it is a beginning in trying to focus on what we can do about health promotion and the prevention of secondary conditions.

Since that time, Dave Moriarty has completed an analysis of the Behavioral Risk Factor Surveillance System data from eight states. The Quality of Life (QOL) Module indicates that people who say they have an activity limitation are significantly more depressed and anxious, experience more pain, have higher levels of sleeplessness, and have less vitality than the general population. All of these factors come together to indicate that this is a public health issue that needs to be addressed, and that is where we need to put our resources. We have done that.

We are now focusing on secondary conditions, on broader, less diagnostically related areas. We are talking about using disability domains so that, rather than just focusing on specific diagnoses, we take advantage of commonalities among those with mobility problems, with communication problems, and with learning problems. There are differences, but there are also similarities. From a public health standpoint, we need to broaden the focus beyond specific diagnoses, which may involve only small groups of people.

To operationalize our emphasis on science, our center just put out two RFPs. The first one was another state cooperative agreement, focusing on the prevention of secondary conditions and health promotion. Part of that is the requirement that the 15 states that we will be funding use the QOL module from the BRFSS to help us do a better job of surveillance. We are going to be adding some questions, and we are piloting those now and sending them to the cognitive lab at NCHS to add some further disability domains and to broaden the scope of QOL. In the second RFP, there were four emphases: conditions among minorities and women, younger and aging populations, assessing cost effectiveness of interventions, and developing measures of levels of participation and characteristics of the environment in which the person lives and moves.

We have to be creative with our methodology. We have to be willing to move beyond the bounds that are often set upon us and that we sometimes set upon ourselves. We hope that these priorities will

allow us to reach a little bit beyond where we are. We want this to add to what NCMRR, NIDRR, Social Security, HRSA, ASPE, and all the other parts of CDC are doing, so that we do work together. One of the things that we do have to do is forge clearer and stronger relationships.

We have to see the disability community as including all of us, those with disabilities and those of us who are temporarily able-bodied. I think we have to celebrate our similarities rather than focusing on our differences. That means that the health community has to be much more sensitive to issues of transportation and housing and economics, but that folks in those areas can't assume that we can do all of those things without being healthy. One of the things that we have to deal with, in terms of science, is to forge a close relationship between the several communities that are part of the larger disability community.

I have several short-term goals, by which I mean the next year or so. First, we have got to add more science. We have got to find the resources to begin to seriously address a national disability surveillance system. NHIS Disability Supplement is wonderful, but it has to be done more frequently than once every forever.

Secondly, we need to look at a longitudinal cohort. The Cancer Society did a wonderful job of growing a cohort; they got women to start volunteering and getting their friends without cancer to volunteer in order to look at risk and protective factors. We need to build a cohort of people with disability, in order to look at secondary conditions. We need to start with the Independent Living Centers, where there is a group that could volunteer, and we could begin to look at the longitudinal issues—risk factors and protective factors that can emerge.

Thirdly, we have to make sure that all of us in the disability community are involved in longitudinal cohorts. Advocates and consumers from within the disability community also have to be involved in any kind of disability surveillance system.

Finally, we need to push more and more for that global disability question on any survey that occurs. We have got to bring some more federal pressure to bear to make that happen.

There are two other things I want to mention. This is probably a longer-term goal, but I would like us all to be able to use the word "disability" and mean the same thing. That would be a dream come true. The ICIDH is giving us a structure, a framework that can provide both conceptual clarity and a taxonomy for measurement that we need badly if we are going to move forward in this field.

Finally, it seems to me that much of this can be synthesized in the Healthy People 2010 objectives, which we are going to be working on in the next six months to a year. We have been asked to coordinate that effort. It is a crucial, pivotal opportunity for consumers, for scientists, and for people in government to come together to provide a vision for what we want over the next ten to fifteen years, in terms of the health and well-being of people with disabilities.

I think we need to make a concerted effort to involve as broad a number of people as we can in framing goals that are concrete and measurable, but also with a clue as to how we would go about intervening to make it different. You can have the greatest measurable, concrete goal in the world but, if you have no way of making a difference in people's lives, then the data is not going to change.

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GLENN FUJIURA
Institute on Disability and Human Development
University of Illinois at Chicago

We have seen dramatic changes in our cities over the past few decades, in terms of the economy, the population, the nature of health risks, and the resiliency of people exposed to these health risks. In particular, we have seen the dissolution of family structure in the city. The essential question here is this: Is the universe of disability changing because of these changes?

There are reasons to believe so. We know that disability is not randomly distributed across populations, and we are in the midst of some significant population changes: aging, for example, and the change in racial and ethnic makeup of the country. We know that the social and economic conditions associated with risk for disability are changing.

These two dynamics and their impact on the character of the larger population of Americans with a disability can play out in a number of ways. There could be new etiologies or changes in the magnitude of the etiology threats. We have shifts in the character of the larger population that have direct or indirect impact on the manifestation of disability.

Even in the absence of direct empirical linkages of cause to outcome, there are reasons to believe that the population of Americans with disability is changing in some fundamental way. The basic premise was laid out by Kate Seelman and Sean Sweeney in an article and in a number of presentations that attributed basic changes to some features of the economy and the environment. The features that were mentioned included violence and abuse, aging, substance abuse, inadequate prenatal care, low birthweight, adolescent pregnancy, poor nutrition, environmental hazards, and so on.

As I have puzzled over possible changes in the population, it has become clear that little would be gained by thinking in terms of very straightforward, uni-dimensional, very specific causal models. I believe the idea of causes that are embedded in a social and environmental context is simply too complex and too confounded to address very simply. So the research of our center focuses on a few major themes that are deeply intertwined and interrelated: poverty, the status of disadvantaged minority groups, and what I have loosely labeled "the transformation of the American cultural and social landscape."

Although race and ethnicity has received growing attention over the years, we have only recently begun to systematically address the issue of the non-random distribution of disability across racial and ethic groups. The general pattern is very robust. It holds up across different data sets and different conditions. We see that, for the most part, rates of disability are lowest among Asian and White populations and highest among African Americans and Native Americans, with Hispanic/Latino populations somewhere in an intermediate position. Of course, it is not race or ethnicity *per se*, but rather the markers that are associated with race and ethnicity: educational attainment, access to health care or insurance, where one lives, exposure to other risks, and so on—all of these things that are bound together by poverty.

Whether as a condition of risk or as a consequence, the link of poverty to disability is unambiguous. A large percentage of Americans with disability are of low income or poverty status. Generally, the strong inverse relationship between family income and childhood morbidity holds up across all types of health conditions.

There are reasons for the apparent non-random distribution, and they are hardly a mystery, at least on a broad, conceptual level. The distribution of risk and the exposure to risk and vulnerability is highly skewed in America. Ethnic and racial minorities and the most vulnerable—children and single parent families—are disproportionately affected. Over the last two decades, 25 to 36 million Americans lived at or below the poverty level. Of the 15 million children under poverty in 1995, 5 million were black and 4 million were Hispanic. A majority of these are in female single-parent households. This is an old story—poverty and the discrepancies across racial and ethnic groups are a stable feature of all of our discussions about demography and our policy deliberations.

Central to the premise of this idea of the changing universe of disability is the fact that the contours of risk may have undergone a generational change. The causes are based in the social context, which is an important object of systematic analysis—more than just a control variable covariate.

By way of example, I want to discuss very briefly violence and low birthweight. Mortality data is well represented in our violence statistics,

but we know very little about the consequence of non-lethal violence. I won't even begin to explicate the issue of violence in America, except to say that the sheer magnitude of the number of injuries suggests that there is a significant component that could potentially lead to injury or to long-term disability. Despite the apparent stability in the overall statistics and the widely publicized declines in rates of violence in America, the underlying results indicate greater vulnerability among certain populations—minorities in the inner city. Thus, for example, rates for young minority males in central cities are at historic highs. Secondly, while we are not quite sure what the etiological basis of low birthweight is, the associated components of low birthweight are very much embedded in the social context: poverty, education, family structure.

My point is to emphasize the importance of socioeconomic vectors in the manifestation of disability, the importance of data, and the value of multiple strategies to answer what are overwhelming, complex questions.

The notion of social and economic factors is an old one. However, social and economic factors have always been treated as a background variable, as a contextual variable, one that is controlled or held as backdrop to more pointed analyses. This is ironic in many ways, because we are so intensely aware of these larger social issues in all of our research that they are almost ubiquitous in our research reports. Yet they are rarely the principal object of study in their own right.

This is what our project is about. It is about the explicit study of the underlying components of this socioeconomic relationship to the manifestation of disability.

The data needs of this project are very much focused on causes, as opposed to conditions, and I anticipate that our work is going to be far less concerned with specific categories of impairments and their associated conditions than much of the current work is. Our major challenge is to consider risk associated with disability from a systems perspective, rather than on a condition-by-condition perspective. Implicit in this challenge is the issue of surveillance, which is basic to any public health thrust, and one that we are going to spend a considerable effort on at the local level.

Central to the socioeconomic basis of the disability theme is the value of person-environment data, the interplay between the individual and the resources and limitations of the environment. Our emphasis on social and economic issues is a natural extension of the disability studies concept, for example, the issue of preventable secondary conditions or the exacerbation of existing conditions because of the lack of access to services.

Finally, our task is as much about learning what kind of questions to ask as it is coming up with immediate answers, because the problems we are dealing with are so overwhelmingly complex. I have conceptualized the project in terms of one of my favorite metaphors: Research is very much analogous to the human visual system, where we don't directly see so much as we reconstruct the environment around us. The research project will pull together different images at different levels of analysis.

Embedded in the changing universe theme is the notion that some of the concerns and policy issues of Americans with disabilities transcend the fact of disability, that these are really issues for all Americans in the health care system and American policy in general. To the extent that disability statistics can facilitate a policy dialogue or galvanize policy decisions, then these statistics must be used to highlight the impact of the concentration of poverty among certain subpopulations of America and the maldistribution of vulnerability in our nation.

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JOHN HOUGH
Office on Disability and Health
Centers for Disease Control and Prevention

Data from the National Health Interview Survey show that hospital discharges for asthma have remained nearly constant during a 14-year period, while prevalence has increased by nearly three-quarters. According to the 1994 National Health Interview Survey, there were an estimated 14,562,000 cases nationwide. The estimated prevalence among all ages was 56.1 cases per thousand persons, but among children under 18, the rate was 69.1 cases per thousand.

The rates for Caucasian and African American young adults are nearly the same: 58.2 versus 58.9 cases per thousand. However, among older persons over 65 years of age, there is a substantial rate difference: 51.9 per thousand for Caucasians versus 44 per thousand for African Americans. Rates also vary by income. Among persons under 45 with lower incomes, the prevalence is estimated at 84 per thousand, versus 50.9 per thousand for those with higher incomes.

In data from the National Hospital Ambulatory Medical Survey from 1993 and 1994, children under 15 years of age have an estimated 73 asthma-related ambulatory care visits per thousand persons. That indicates heavy utilization of ambulatory care services. The volume of children seen in emergency departments far exceeds the volume seen in emergency departments for other age groups.

By gender, females are more frequent utilizers of asthma-related services than males. Looked at by race, the rate among African Americans is more than 50 percent greater than the rate for Caucasians: 75.1 per thousand for African Americans versus 48.9 for Caucasians.

According to the American Lung Association (ALA), asthma prevalence among African Americans is reportedly 22 percent higher than that for Caucasians. One in five Hispanic children had symptoms of asthma, also according to the ALA. There was also an interesting study last November in *The Journal of Pediatrics*, reporting that one in seven children in a cohort of inner-city Detroit school children, ranging from third through fifth grade, had undiagnosed asthma. This suggests that, in addition to the existing increasing burden of asthma, there is also a burden of undiagnosed asthma that may be just as serious.

Moving on to secondary conditions, according to the Disability Supplement of the 1994 National Health Interview Survey, nearly one in four elderly respondents with asthma, or 23.4 percent, reported difficulty walking three city blocks, suggesting the existence of a burden of secondary mobility problems related to the primary impairment of asthma.

In summary, my key points are as follows: First, the distribution of disabling conditions due to asthma is not only increasing, but it also disproportionately affects members of the lower socioeconomic strata. Secondly, children are heavy utilizers of expensive services, such as visits to emergency departments. Third, evidence exists that environmental factors, like secondhand tobacco smoke and insect infestation, are associated with elevated asthma prevalence. Finally, there may be an inner-city prevalence gradient that is worthy of further research.

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JANET GUERRERO
Center for Injury Prevention and Control
Centers for Disease Control and Prevention

I would like to discuss non-fatal injury, in particular non-fatal firearm injury and traumatic brain injury (TBI). At the Injury Center, we know that we have to monitor disability from injury. However, current data systems are unable to provide trend data to document injury related to disability on a population basis. We are working on it.

Together with the Consumer Product Safety Commission, the Injury Center conducted a study utilizing the National Electronic Injury Surveillance System to monitor non-fatal firearm injuries. Firearm injuries are defined as "penetrating injuries or gunshot wounds caused by any weapon that uses a powder charge to fire a projectile." Ninety-one hospitals across the nation participated in the study, and data was gathered from 1992 to 1995. Lee Annest from the Office of Statistics at the Injury Center was the lead investigator, in collaboration with James Mercy, Delinda Gibson, and George Ryan.

We found that the rate of non-fatal firearm injury is approximately two-and-a-half times greater than fatal firearm injury. We also found that the non-fatal injury rate for men, at 68.7 per one hundred thousand population, is nearly seven times greater than that of women, who experienced a rate of 9.9.

African Americans are disproportionately affected by non-fatal firearm injuries, constituting nearly half of such injuries. We also found that young persons 15 to 24 are disproportionately affected, and their rate was 119 per one hundred thousand. These findings are very consistent with the mortality data we have regarding gender, race, and age.

The next question would naturally be: How many of these injuries result in a disability? That we don't know yet. However, we do have information on the body part that was affected, which will provide a glimpse into the types of disabilities that persons who experience these injuries face.

The largest proportion of firearm injury is accounted for in injuries to the limbs, constituting close to half of all of such injuries. This is not unexpected. No vital organs reside in your limbs, and the likelihood of survival is high. People experiencing these injuries will certainly experience a temporary disability, or possibly a permanent disability, depending on the injury's severity.

We also see injuries in the lower and upper trunk, which constitute between 31 and 33 percent of the injuries. We all know that, if people are hit in the spinal cord, they will live with a lifelong disability.

Finally, injuries to the head and neck constitute 14.6 to 17.6 percent of firearm injuries, rising consistently over the three years of the study. In a firearm injury to the head, either the bullet will graze the head and the person is not likely to have a disability or it will penetrate the skull and cause a traumatic brain injury. The consequences of traumatic brain injury can be far reaching. It can lead to changes in executive functioning, such as initiation of new tasks, planning and execution, and speech and/or language production and comprehension, known as "aphasia."

Some TBI victims no longer comprehend or recall words they used to know, and they find it very difficult to learn new words. Reasoning and problem-solving skills all become diminished. Learning and attention span may be diminished. Behavioral changes can include increased disinhibition, increased aggression, irritability, and loss of emotional control. Many TBI survivors experience headaches, dizziness, anxiety, and depression. Persons with TBI experience varying degrees of cognitive and behavioral disabilities; a change in any one of these areas will affect personal and professional relationships.

Much of what we know today about TBI comes from hospital-based clinical case studies or focus epidemiologic studies. Though useful, these systems have not provided the ongoing population-based incidence, prevalence, and etiologic information necessary for planning and evaluating public health programs for TBI.

To address this issue, the CDC Injury Center funded four states in fiscal year 1996 to conduct TBI surveillance. We are expanding this summer to include eight to ten more states. These systems will be responsible for collecting statewide data on occurrence, circumstance, cause—including firearm and violence—and outcome variables, that is, severity and the prognosis of disability. They will not only collect mortality data, but they will collect morbidity data as well. We believe that, in the next three years, these state projects will be able to provide quality data, documenting trend patterns and

outcome variables of TBI. We eagerly look forward to working with our partners in this endeavor.

But what do we know now about TBI and firearm violence? First, let's look at mortality. We know that firearm TBI is a large contributor to the overall mortality rates. We also know that traumatic brain injury caused by a firearm has a very high fatality rate; estimates range between 80 and 92 percent.

With the help of several states, we were able to determine some hospitalization and mortality rates for 1990 to 1993. The participating states were Colorado, Missouri, Oklahoma, and Utah. The hospitalization rate for that period was 85 per one hundred thousand. The overall fatality rate was 23 per one hundred thousand, which includes the non-hospitalized fatality of persons who died prior to admission into the hospital. The overall rate for TBI was 103 per hundred thousand.

We also know from this data that 10 percent was attributed to firearms, and 9 percent to other forms of assault. So we can crudely say that almost one-fifth of the TBI mortality and morbidity combined were due to violence. From this data, we can crudely estimate that approximately 2,000 to 2,500 people each year suffer a non-fatal TBI from a firearm and subsequently develop a disability. Of course, this estimate will be revised as data from currently funded states comes in.

However, I would like to emphasize that this estimate is for TBI firearm injury alone. There are other injury events that will add to this estimate. For example, penetrating wounds from knives or other sharp objects, or blunt diffused trauma from physical abuse, such as spousal or child abuse. We certainly need to better define and understand those causes, as well.

In closing, I would like to emphasize the importance of the continued support of data collection efforts and collaboration with these state projects to gain a better understanding of the magnitude of TBI and the disability outcomes from all causes.

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DISCUSSANT: JANE WEST

Jane West and Associates

I want to make three points in relation to how policy and research may intersect and may fail to intersect: first, the progress that we have made since ADA in the area of the intersection of policy and data; second, a couple of reflections on what we heard this morning in terms of data trends and how that may influence policy; third, a few specific suggestions about what we might do, or what we might work toward doing, to further imbue the ADA principles into some of our data collection and research.

First, in terms of progress, a lot of people have alluded to the conference that the National Council on Disability held in 1992, looking at how to translate the ADA into research. I remember speaking at that conference and reflecting on how very little data had influenced policy. One of the examples I gave was that, when the Americans with Disabilities Act was being considered, there was one piece of data that was quoted over and over again. It was the result of a Harris Poll, saying that two-thirds of people with disabilities weren't working but wanted to. It wasn't a SIPP analysis. It wasn't a Census analysis. It wasn't a Health Interview Survey analysis. It was a Harris Poll.

I used that example at that time to say that there isn't much relationship between policy and data. I have changed my mind. I believe that, if you look at the evolution of disability policy, there was incredible progress during the 1970s and 1980s. To me, that marked a turning point, in which the issues in policy that we are dealing with now—Social Security, health care—have become increasingly more complex and more in need of better and more accurate data. I think that has been somewhat of a shift.

Another example of the progress that we have seen is the disability community's increased interest in data, since the passage of the ADA. At a conference of the National Council on Disability held in Dallas last year, Mitch LaPlante presented preliminary data on disability trends. This was a group of consumers, two or three hundred people with disabilities from all over the country. People were fascinated by his presentation. He had a lot of questions. There was a lot of interest and enthusiasm.

One question to ask is this: Have we seen data influence policy more in the disability area? An example that comes to my mind is the formula funding in the Individuals with Disabilities Education Act, which just passed. The law shifts funding from child count to formula funding over time, and that formula is weighted for poverty. I think that is in reflection of the acknowledgment of the long-standing association we have known between poverty and disability.

A second point that a lot of people touched on has to do with the different things we measure: impairments and chronic conditions, for one; access to services, to assistive technology, to health care, for another; and third, outcomes, such as the extent to which people are increasingly being employed and increasingly participating in society. These are three different notions. I am not sure how clearly we have them articulated or separated.

I am concerned that, when we see a headline in *The New York Times* that says that the disability prevalence of elderly people has dropped significantly, if I am a Member of Congress looking for a way to cut funds, I am going to say, "Cut Medicare! There is not as much need any more." On the other hand, if we see that there has been a great increase in disability among children, I might think: "Okay, then the rate of children on SSI should increase." Not necessarily. We have seen an increase in access to the kinds of services that young people need to be in school and to be productive. I think we need to work more toward clarifying these different aspects of trends and what they mean.

I want to give some examples of what might be done to further promote this notion of infusing an ADA paradigm into some of our data collection and analysis efforts. First, the research community needs to continue working together with the disability community. If you are going to have a research data collection meeting, make sure you have people from the disability community there. Likewise, when the disability community is having advocacy meetings, make sure there are some research people there. Make sure that the data is brought in.

Secondly, I think that we should consider expanding both the mission and the resources of the Interagency Committee on Disability Research,

as well as funded entities like the Research and Training Center at the University of California at San Francisco, to specifically look at this translation. What does this really mean in terms of a particular data set? There ought to be focus groups with people with disabilities about what they would like to know.

Certainly, the Health Interview Survey Disability Supplement is a gold mine. That was an incredible effort to bring the disability community and the tenets of the ADA into a data collection instrument that I think is going to reveal some really interesting things to us.

We need to market the analysis and the results of so much of the data that is out there. I believe that, if you asked the average disability advocates whether they knew about the Supplement to the Health Interview Survey, they wouldn't. I think that the information that is in there is going to be rightly relevant to them. I think more marketing of what is there, what is available, and the nature of the information would be helpful to further bring together these two worlds.

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GENERAL DISCUSSION

Greg Goodale, American Rehabilitation Association:

There is proposed legislation called The People with Disabilities Health and Wellness Promotion Act. I was wondering how much that would benefit the CDC and, in particular, Don's Lollar's mission?

Don Lollar:

It would substantially aid us, and aid public health, because what we had in mind for use of that money includes developing the National Disability Surveillance System and developing what might be called "Centers of Excellence" around disability in public health departments. And expanding health promotion activities in many more states than we are able to do now.

Bob Griss, Center on Disability and Health:

This session has used the term "public health" a lot, but it seems to be a monitoring function, as opposed to public health interventions that actually make a difference in people's lives. Given the fiscal constraints in our public system, and particularly the vulnerability of the public health system and the shift of resources to the private sector, I am looking for public health strategies that are more effective interventions that would be embraced as a way of more effectively improving the health of the population.

When I see statistics on the distribution of disability, I translate it into ADA terms. Differential rates may actually be translated into differential access to services, and many of those services are public services. In fact, even our private health care system is publicly subsidized. A majority of our health care expenditures are public dollars, not private dollars. Our challenge is translating the ADA philosophy into a system of public accountability for outcomes.

For example, if you see asthma rates higher in certain areas, we should hold health care plans accountable for failure to do the outreach that is necessary to change those rates, because we are, in a sense, depriving people in the inner cities of having equal quality care. Therefore, the challenge is not just to invent a public health monitoring system, but to get the public outcomes, to identify sources or responsibility for changing those public outcomes.

If, in your health care system, you see that there are people who are not getting equal access to quality care, that becomes a civil rights issue. When the insurance company says, "Well, we can't do it in a cost-effective way," that is not an adequate solution, just as it isn't when public accommodations say that when you tell them that they have ADA obligations. We need to translate the ADA philosophy into expectations about how publicly funded systems function, and that includes the whole health care system.

I really think we do ourselves a disservice by focusing on surveillance, unless we are holding health plans accountable for quality outcomes and making that a contingent for licensing. You see, if state licensing decisions were based on providing quality care, then we would begin to have a health care system that is responsible and accountable for the kinds of differential rates that you are able to show out there. But, in fact, we are talking about public health as a separate function, and I think it doesn't have the leverage that it needs to have.

Mitch LaPlante:

What we mean by "monitoring" is both public health and social monitoring. When changes occur that have an influence on disability, we would like to have our pulse on what these changes are and put in interventions that can help to diminish an increase in disability. Or, if disability is going down, to know that certain interventions are responsible for that. I think the frustration is that we are rather far from having a system of disability surveillance that can achieve that, and the CDC is trying to build this, and they deserve credit for taking this step.

Don Lollar:

What the disability program has done in the last eight years is to put money into states. For the next four years, $5 million a year will go to states—with an advisory council composed of 25 percent people with disabilities—to decide on strategies for health promotion and prevention of secondary conditions within their states. Our notion about public health is to try and be involved as clearly as we can with state public health folks, with consumers throughout this country.

SESSION 4:
BUILDING BETTER TOOLS FOR DISABILITY TREND MONITORING

DAVID MORIARTY
National Center for Chronic Disease Prevention and Health Promotion
Centers for Disease Control and Prevention

I will briefly describe the origins of our quality-of-life surveillance program, discuss some measures we are using, make reference to some validation projects that we are supporting, and then present some of our analysis.

There are three major trends or influences that got us started: first, the Year 2000 objectives goal of increasing the proportion of life that is perceived as healthy and functional; second, the "Disability in America" conference earlier this decade, which placed very strong emphasis on the importance of measuring functional status and quality of life, both in the general population and for persons with disability; third, state-based health reform, both on the health care side and on public health, with emphasis on measurable outcomes.

Specifically, we got started out of the CDC Aging Studies Program that was created in 1990. We recognized the importance of having a public health outcome measure other than mortality and morbidity, and we sought to develop quality of life as such a measure. We called together an expert workshop in 1991, and we were told that it was important to focus on functional status as a key component of quality of life.

We came up with four questions to put on the Behavioral Risk Factor Surveillance System (BRFSS) core questionnaire and, since January 1993, these questions have been asked of all adult respondents. Our expert group said to ask the "gold standard" self-rated health question, and then ask about recent physical health (i.e., days in the past 30 days on which physical health was not good), mental health (i.e., days in the past 30 days on which mental health was not good), and activity limitation (i.e., days not able to do usual activities due to poor physical or mental health).

We also came up with 10 additional questions that were optionally available to states, beginning in 1995. The BRFSS is a continuous state-based telephone health survey, based on a systematic sampling procedure, but it is really 50 surveys done each month by all 50 states. It is not meant to be a national survey, but the fact that all 50 states participate allows national estimates to be made. About 12 states have used the additional questions for a year or more since January of 1995.

Basically, we are asking five questions on activity limitation, including the NCHS question: Do you have any activity limitation? Then, if so, what is the major cause of it? How long have you been limited because of this cause? Do you need personal care assistance or routine care assistance? Everybody also gets asked questions on pain in the past 30 days, as well as depression, anxiety, sleeplessness, and vitality.

We put a great deal of emphasis on validation, because in the quality-of-life area this is a critical issue. People tend to be skeptical about self-reported measures, particularly at CDC, where they are used to looking at everything under a microscope and identifying particular organisms.

It is more difficult to pinpoint quality of life. We and others, including the NCHS cognitive lab, have done various studies in order to understand exactly what we are measuring. We have done a construct validation to see how the notion that we are measuring matches up with other similar concepts. We are also funding some criterion analyses, including two separate projects at the Saint Louis University School of Public Health. The first one looked at a community population and cross-validated our 14 quality-of-life questions with the Medical Outcomes Study Short Form 36. A preliminary report shows that our items correlate, as expected, with the subscales and the summary scales of the SF-36. Also, the 14 items generally discriminate groups with chronic conditions and groups that are believed to have mental depression similarly to the SF-36.

We now have access to data from 8 states that used the optional quality-of-life module in 1995. We are now analyzing that data. There were about 13,000 persons total for the eight states, and the

data hold up very nicely on both the aggregate and the individual state level. We find that the group with the most impairment from these secondary, quality-of-life conditions is the group that says that they are unable to work. And that is true in every case in every one of the 8 "recent days" measures.

What especially struck us, from all of our analyses to date, are the extraordinary differences based on the level of reported activity limitation. The group reporting no activity limitation also reports a very low mean number of recent days of bad physical health (1.7 days), 2.4 bad mental health days, and 0.8 activity limitation days. But those numbers go up dramatically as the degree of limitation reported increases. It goes up in physical health from 1.7 to 19.9 mean days; mental from 2.4 to 9.3; activity limitation of 0.8 to 16.9. There are similar patterns with pain, depression, anxiety, sleeplessness, and vitality. It makes a very strong case for the problems of secondary conditions relative to disability.

For example, when we look at mean days of pain in the past 30 days, we find that, once again, for each increasing level of self-reported disability, there is an increase in symptoms. The same holds true on the mental side, with recent days of depression.

In another project, we asked a group at Case Western Reserve to estimate the prevalence of various types of disability using data from the 1993 through 1995 Behavioral Risk Factor Surveillance System. They have started with severe work disability, which they defined by looking at the core items in the BRFSS and matching them up with the NHIS module on activity limitation that more directly asked questions about work disability. They then developed some small-area projections with a logistic model. Their county-level estimates of severe work disability for persons aged 18 to 64 years range from less than 4 percent prevalence in some counties to 8 percent or more prevalence in others. This information gives each state some potential for looking at areas of the state where they might want to concentrate some of their efforts.

In conclusion, we at CDC feel that validation of measures is very important, and we intend to emphasize it. We have to know what we are measuring. We just can't take on faith what people report to us, even if it matches up internally with other aspects of the questionnaire. This is also crucial if we were to use these measures in managed-care settings and talking about health outcomes.

Furthermore, I would like to reinforce a comment made by others for using global measures. Take those four core questions. We would like to see everybody put those on all their surveys so that we can crosswalk from one survey to another. We have data now to show how those four questions relate to the Short Form 36, which is a very well validated and widely used clinical instrument.

Another recommendation is to look at community-level indicators of disability, as was already discussed.

One other item that we think is important, and that the BRFSS can give us some insight on, is seasonal patterns and time trends. The BRFSS is organized so that one-twelfth of all the surveys are done each month. So you can look at it month by month to see if there are any seasonal patterns. We think this might be particularly interesting in the area of disability. Just anecdotally, people talk about problems in the northern areas, where you can't get outside and get around in the winter time.

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GALE WHITENECK
Craig Hospital

In January, we held a CDC-funded conference in Denver that pulled together a couple dozen experts, with representation from state health departments, from academic centers involved in the study of disability, and from research centers. It also involved CDC staff members. The basic question asked at that conference was: What is the public health role in disability surveillance?

The public health roles, broadly stated, are primarily information gathering, dissemination, intervention, education, service coordination, health assurance advocacy, and regulatory reform. But the group described the public health role of disability surveillance specifically as meeting the information needs of a wide variety of entities, including federal, state, and local public health agencies, as well as the many governmental agencies involved in disability, the public and private sector service providers, health care planners, and disability advocates.

The goal of disability surveillance is thought of as the use of the science of epidemiology to better understand the incidence, prevalence, and impact of disability. It is often characterized by ongoing population-based surveys that identify the problems, needs, outcomes, and resource utilization of people with disabilities.

Although the Denver group felt that the ultimate goal of disability surveillance was to help improve the lives of people with disabilities in a wide variety of ways, there was also a clear recognition that the method of improving lives will be primarily indirect, through the use of data by other entities, as opposed to direct intervention.

What data is requested? Participants reported an overwhelming number of data requests. The numbers of people with disability was the most frequently asked question. Only secondarily were there questions about the nature or the characteristics of disability, and there were very few queries regarding the impact on the lives of people with disability, or measures of outcome.

We discussed various methods for disability surveillance, including general population surveys and cross-sectional surveys of people with disabilities—either categorically defined groups of people with disabilities based on a medical diagnosis or a non-categorical approach based on functional limitation. The NHIS Disability Supplement is a good example of a cross-sectional survey of people with disability.

We also saw the need to be moving toward longitudinal surveys of people with disability. The Colorado Traumatic Brain Injury Follow-Up is one example, in which a population-based registry of persons with traumatic brain injury is being followed on a regular basis. Community surveys are a fourth category of major data collection methods that might be involved in disability surveillance, and social indicators are an example of that.

The group felt that several domains of information were important:

- Health status—not only health status measures directly but also checklists of secondary conditions, including measures such as the SF-36, the HSQ-12, the Quality of Well-Being Scale, the four core items and the 10 supplemental items of the BRFSS, and the Montana Secondary Conditions Survey.
- Disability itself, focusing on the magnitude and severity of functional limitations, with the NHIS Disability Supplement and other ADL and IADL scales being examples.
- Handicap, to use the terminology of the World Health Organization, or participation, or community reintegration. The focus would be on the extent of return to productive activities in the community, with the Craig Handicap Assessment and Reporting Technique and the London Handicap Scale being examples of potential tools that might be used in disability surveillance.
- Quality of life, with a focus on subjective perceptions by individuals with disability about their perceived quality of life. A variety of tools have been suggested there, everything from the single-item question on quality of life or life satisfaction to the Deener Scale, which is a five-item scale.
- Service utilization, with an interest in the full range of health and social services that might be utilized by people with disability, addressing not only the use but the cost of barriers and unmet needs. The NHIS Disability Supplement is an example of how that data might be collected.
- Demographics, with particular interest in

health insurance variables, socio-economic status variables, the principal diagnosing condition, onset of disability, and etiology.

- Health behaviors, as exemplified in the BRFSS, including both the protective and risk behaviors that people might engage in.
- Disability beliefs, including the orientation to disability and coping strategies, with an example of this type of assessment being some of the Harris polling.
- Community assessment, focusing on compliance with ADA and environmental issues.

Our group of experts identified three important disability surveillance products that needed further work:

- A general-population disability screen. The primary issue is one of case definition. Survey researchers define disability in terms of limitations of several different things: major activities, or IADLs and ADLs, or specific functions, sometimes a broader range of physical and cognitive functions. Clearly, a more common definition would help in the comparative analysis from various data sources. It is also clear that we need to have a measure that will appropriately catch individuals with disability, whether that disability results from injury, chronic disease, birth defect, or developmental disability. There's also the issue of whether the limitation is assessed with or without a device or person to aid, assistance being a key issue.
- A disability surveillance instrument. The goal here would be to design a tool that would be comprehensive and allow the assessment of information covering the nine domains that I mentioned earlier. It would be applicable across the range of disability categories, either from a diagnostic medical approach or from a category scheme that defines the type of disability in terms of mobility or personal care or communication or learning limitation. It would also be usable in either cross-sectional or longitudinal research.
- A disability surveillance design. The group felt that there needed to be a more comprehensive approach to a disability surveillance system that included not only case definitions and content of measurement tools, but also methods, sampling strategies, and scope. The costs of this larger endeavor would need to be addressed as well. This would need to be considered both from a national and a state-level perspective. Clearly the first step would be some practical improvements that could be made on existing methods, and the incorporation of four specific items from the BRFSS and other tools to allow crosswalking. But we also need to think more broadly as to what a disability surveillance system should look like in the future.

In conclusion, it is clear that accurate numbers are important. This meeting demonstrates the desire to have more accurate rates of disability, but if the data on counts and rates are simply not enough to meet the needs of disability surveillance, we need outcomes of the disablement process to be assessed. In particular, I felt that participation or handicap or community reintegration—the full participation concept from the ADA—needs to be an outcome that we can assess better in disability surveillance work.

Also, we need to focus on various determinants of that outcome of full participation, in order to identify what aspects are predictors or causes of an individual to be either a full participant in society or less than a full participant. In particular, environmental factors and their relationship to disability would be singled out as an area that has not been adequately addressed.

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JAMAL MAZRUI
National Council on Disability

The National Council on Disability held a major summit about a year ago in Dallas. This summit brought about 300 consumers together from around the country to develop a long-range vision of disability policy. One of the recommendations from the summit was to promote greater involvement by people with disabilities in the design, conduct, and dissemination of research and data collection that affects people with disabilities.

Toward that end, we will be sponsoring a meeting in conjunction with NIDRR in June. We are bringing together researchers and consumers to try to increase communication between groups that have often, unfortunately, not had good communication. As part of the preparation for that meeting, we sent out a list of questions. I am going to answer those questions here from my own personal perspective as a blind consumer. I will divide those into three areas: design, conduct, and dissemination of research.

In terms of design, we are basically asking consumers and researchers the same questions, but for each to answer from their end of the question. As a consumer, to what extent have I been involved in the design of research affecting me as a person with a disability? I can't say that I have been consulted on any federal research initiative.

But I want to make the point that I believe it is very important for people with disabilities to be consulted in the design of research. I have worked with a university and have been a graduate student, and so I think I have some sense of that environment, and I think there is a tendency for researchers to feel that they know what needs should be studied and what questions need to be asked. They feel that is a matter of scientific inquiry, and there wouldn't be much that a lay person would contribute to that endeavor.

But the reality is this: As economists teach us, resources are scarce, including resources to do research. So why not focus research on things that will be most helpful to people, given that you have limited money and staff to do research?

I submit that, if researchers held more focus groups with people who have disabilities, they would get a better sense of what kind of research initiatives would really make a difference in people's lives. Their research would then be better able to inform public policy to create more effective interventions leading to fuller participation in society by people with disabilities.

I think that one important distinction is whether the research is ultimately aimed at preventing disability or aimed at minimizing the effects of disability. Both are important, and certainly CDC and other organizations have a very important public role in trying to develop data that helps us account for the prevalence and distribution of various disabilities and help us design public health programs that minimize the occurrence of disability whenever it can be prevented.

The frame of reference changes, however, from the standpoint of people who already have disabilities. Because we can't have it prevented for us, our main concern now is: How can the effects of that disability be minimized so that we can live as full and productive and happy a life as possible?

I submit that researchers tended to emphasize prevention of disability over minimizing the effects of disability or the handicap of disability in society, partly because we are a minority as people with disabilities, albeit a significant one. But because of that, researchers tended to cater to the interests of the majority population, which was afraid of ever having a disability.

As we have learned from the resourcefulness of people with disabilities and from the lessons of what can be done through assistive technology, no longer should the concept be that, once you have a disability, you have given up hope because the prevention effort is lost. Instead, it is very important to look at how life can be made as full and equal as possible for people who have disabilities and to believe that there is much hope and potential for that to occur.

I, for example, am more interested in issues that measure the participation of people with disabilities in society—people with disabilities in general and blind people in particular. What percentage of blind people are now employed and in what professions are they employed? How many people with disabilities have access through personal computers to assistive technology? How many are connected to the Internet? What percentage have decent public transportation available to them? What are the earning levels of people with disabilities compared to their non-disabled equivalents?

In general, the point is that we want the same

kind of measures of equality in society applied to us as are applied to other groups that have previously been disadvantaged, such as women and African Americans. And of course there is no clear set of measures, but a number have been developed over the years that stand out with some prominence, such as measuring whether affirmative action is still needed. People tend to look at what percentage of blacks are graduating from high school, from college, and what percentage are graduating with Ph.Ds. What percentage are earning within different income ranges?

Another area of interest is the political domain. What percentage of people with disabilities are elected to office or appointed to office, especially in positions that are unrelated to disability? What percentage of people with disabilities are voting?

Moving on to the conduct of research, it is important that research be done in a manner that is accessible to us. In the case of survey research: If it is a written survey, is it provided in Braille and on audio cassette? Is it provided in a way that a person with a disability can independently and privately answer the questions in that survey? Or would they require the assistance of someone else, and therefore lose some privacy or anonymity that other people have?

Of course, there are various kinds of accessibility needed, depending on the disability. For a person who is deaf, if called in a telephone survey, there would need to be an assurance that the person is using an appropriate relay service or TTY machine, rather than just automatically dropping them out of the sample because they can't participate in the normal way. People with cognitive disabilities can often participate effectively if certain adjustments are made, such as using simpler language in the description of a question or using illustrations rather than words, and so on.

In terms of the dissemination of research, I think that the World Wide Web provides an excellent opportunity for information to be disseminated very cheaply and in multiple alternative formats. I would strongly encourage people to take advantage of it. For me, as a blind person, having access to the Web has just opened up worlds of information in real time that were never available to me before.

Prior to the Web, I would only get a subset of information, which was usually delayed because it had to be changed into another format, such as audiotape or Braille. With the Web, I can go online with my talking computer system and get information as current as anybody else gets—and more than I can handle. As you know, that is the major problem with the Internet these days, but for blind people overall, it is terrific. That also stresses making sure that Web sites are designed in an accessible way. It truly can be done so that anybody can access it using a text or a graphical browser, as long as certain universal design principles are observed.

On each Web site, I would encourage not only textual descriptions, but also graphical descriptions and real audio, so that whatever the individual's disability or preference, they can acquire that research and make it useful to them, either in their personal lives or in the advocacy that they do.

One final point, which I think is very consistent with the trend in Congress and in the Administration, is to emphasize outcomes of federal programs, rather than inputs and outputs. Inputs might be such things as funding and personnel. Outputs might be something like the number of people served, which have all been traditional measures of how well the government is performing. As one thinks about it, these are not really the best measures. The best measures would be, to the extent possible, how has that program made a difference in the lives of the people it was intended to serve?

To that extent, the interest of consumers with disabilities are completely in harmony. With regard to employment of blind people, for example, I don't particularly care how much money the government spent or how many people were hired by a VR agency or how many people they gave counseling services to. What I care about is how many people are now in the competitive labor market who were not there previously as a result of that agency's efforts. So I encourage outcome-based research, as well.

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DISCUSSANT:
MARY GRACE KOVAR

National Opinion Research Center, University of Chicago

I am going to make a few comments about how the research mentioned in this session might be done better.

My first reaction to David Moriarty's presentation is that, if you want to make state estimates, I don't think there is any question that you have chosen the right survey. The BRFSS is a state-based and a state-held survey. It is designed for producing state estimates, rather than national estimates.

The only thing you have to be careful about there is that levels of disability are associated with poverty, as well as other factors, and state samples are not always big enough to do that kind of control. You may have to combine a couple of years or combine a few states. You may have to do some other things to make it possible, because I do believe that crude disability rates are not what we need at this point.

I think the BRFSS has one major drawback: It is a telephone survey. To quote Mitch LaPlante's report, *Disability in the United States: Prevalence and Causes, 1992*, "About 5.5 percent of people in U.S. households do not have telephone service. An analysis of that group shows that the rate of limitation is higher in households without telephones (17.2 percent for those without a phone versus 14.9 percent for those with), in part due to the fact that the lack of telephone service is highly associated with low household income... About 2.4 million people with limitation in activity do not have a telephone in their households, a statistic that should be taken note of by survey designers."

Later, in the same book, it also says that, in households without telephone service, inability to work is almost twice as high as in households with a phone. And in households with incomes below $10,000, 20 percent lack phones.

Mitch said that it should be taken into account by survey designers. I think it is even more critical that it be taken into account by survey analysts. If you rely totally on households with telephone service, you are going to badly underestimate the prevalence of disability in this country.

Another point is this: People who are deaf frequently get left out of telephone surveys because they cannot talk on the phone. I think the situation may be a little worse than Mitch said, particularly for this survey and particularly for state estimates.

In November 1994, there was a supplement to the Current Population Survey that was designed to measure telephone and computer penetration in this country. The analysis isn't a sophisticated one, but it does show several things that are very critical to this discussion. Overall, the rate of telephone penetration was 93.7 percent. Less than 80 percent of the poor people in central cities had telephone service. In rural areas, only about 76 percent of the Native Americans, 79 percent of the Hispanics, and 77 percent of the households with a head under age 25 have a telephone.

Population density, race, ethnicity, and income vary among the states, and so I think it is safe to assume that the telephone coverage is also going to vary among the states. Your comparisons could be very much affected by that. I am not saying you shouldn't do it, but that you should be careful. There have been some techniques developed to adjust for this sort of thing, and some of the research that has been done for the National Immunization Survey might be very useful to you.

I want to make a few comments about Gale Whiteneck's presentation. I think that the conference that Gale reported on could be taken and could be developed into the first step for the kind of change brought about by Healthy People 2000. I would like to see that happen.

The Healthy People conference was so successful because it was very specific in terms of goals. The conference Gale spoke about, on the other hand, treated disability as if it were all alike and all homogenous. And it is not. I am not trying to go back to a diagnostic classification. I don't mean that at all. What I do mean is that, for example, when we talk about disability among the oldest old, we are really talking about assistance. In the working-age population, we are talking about whether the person can work, use public transportation, do all these things that are age-appropriate.

I don't think there is a one-size-fits-all surveillance system. I think you have to know what it is that you want to concentrate on and what you want measured. Are we talking about blindness? Are we talking about deafness? Are we talking about wheelchair use? These are all different things. They have different impacts. They have different postponement/prevention measures. They have different requirements for health and social services. I think it is really critical to be specific about some of this.

When Gale was talking about the four ways of collecting data, I think he missed a very important one, probably newer than some of the others: examining people to see whether they can do things, or performance testing. It was used in part of the third National Health and Nutrition Examination Survey and is being used in the Women's Health and Aging Survey. And it will probably be used in the Disability Evaluation Study, which is being planned by the Social Security Administration, in which they ought to draw a national probability sample and examine the people and determine, under the Social Security guidelines, their ability to work.

These are population-based, community-based, household surveys. You can't afford to do it for everyone, but you can consider doing it for a subsample to get a different measure.

Finally, I want to talk about self-reporting of disability. I don't know anybody who knows more about what a person can do than the person himself or herself. It is no good asking my family physician, or whomever, whether I can do certain things. He doesn't know. I do. Furthermore, where do you think medical histories come from? They come from the doctor asking questions and people answering them. That is where we get our information. People know about themselves.

What we cannot answer well is the kind of so-called objective measures that people keep putting on surveys: What was the date of your last doctor visit? How many doctor visits have you had in the last 12 months? How long were you in the hospital the last time you were in the hospital?

I cannot even remember the last time I was at a hospital. The objective things are the things we can't answer well about ourselves. The subjective things we can. I think survey data, interview data, are an excellent source of much of the disability data because we know ourselves.

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GENERAL DISCUSSION

Lois Verbrugge:

I think it is to CDC's credit to be trying out the four new questions since 1993. It is the only example in the United States right now in which there is a genuine effort to do work on a single item to measure disability. For the most part, U.S. researchers gasp in horror at the thought that you can ask about disability all in one.

But the issue is much more appealing within the European community of disability researchers, and there is much more effort. It is a very difficult issue. It should not supplant or replace detailed items about disability. The goal is to see if it is possible. Not with the presumption that the answer is there, but see if one might have, as a companion to detailed diagnosis, also a summation item that would be akin to the parallel development between self-rated health and detailed questions.

The parallel effort in the European arena is being spearheaded by the International Network on Active Life Expectancy. That group now has recommended trying out global disability items in the next several years and presenting the results on the qualities and differentials at the next meeting.

Scott Brown, Office of Special Education Programs, Dept. of Education:

It seems to me that this session today has suggested a topic for next year's Disability Statistics and Policy Forum, which is the environment and building a science toward the study of it.

One of the other things that has become clear is that there is a difference between an approach to the environment, which looks at it as merely the context in which people engage in actions and activities, and a more universal design approach, which looks at the environment as something that affects us all. What are the critical issues that need to be looked at in the environment, from a universal design perspective?

Jamal Mazrui:

One thing that initially comes to mind is the electronic environment, because that is playing a larger and larger role in all spheres of life. I think there is a real opportunity to make that very accessible to people with all kinds of disabilities. So data that could help to measure that would be helpful.

Jane West:

We need to look not only at the environment. For example, does a particular individual own a computer, and is it accessible to someone who is blind? Do they know how to use it? It is not enough to just measure the person and then just measure the environment.

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KEYNOTE SPEAKER

KATHERINE D. SEELMAN
Director, National Institute on Disability and Rehabilitation Research

I have a couple of things that I wanted to share with you as you talk about trends in disability prevalence. For me, it is within the rubric of what we refer to as "the new paradigm of disability," and what that means to the research community. The new paradigm of disability has its origins in the advocacy community, where it is referred to as independent living and civil rights.

Whatever it means to the advocacy community, it has never really been converted into a research agenda. It is my challenge to all of us, as I speak to groups now, to think about what the new paradigm looks like when it is transformed into a research agenda.

There are certain elements, certain domains, as they say in the ICIDH, and certain underlying values that we need to consider if we are to start explicating the new paradigm. Undoubtedly, demographics would be important, and diversity and age span would be among the underlying values. Another domain very near and dear to NIDRR is the environment, however it is defined, and I wait for all of you to define it.

You know that one of NIDRR's signature efforts is an engineering center that contributes to universal design, to accessible telecommunications, accessible environments, accessible products, and accessible transportation. That is a very concrete thing. How do we conceptualize it and create a framework, a conceptualized framework?

Still another domain or concept in the new paradigm in disability would be the scope, and it seems to me that it would be international. There is no doubt that the new paradigm would be based on science, in terms of authority, but based on the disability community, in terms of legitimacy. I challenge all of us to really think about what that agenda is. The advocates have done their work. It is time for the research community to do more there.

In addition to the new paradigm of disability and what it means from a substantive and conceptual standpoint, there is a second orientation for me: research administration and research management. It seems to me, from the standpoint of the new paradigm, that we have to bridge the individual as a unit of analysis. Most of you deal with that unit of analysis in your studies, as well as social entities and the environment. Collaboration, the bridge between health and the health professions and engineering professions, is something we need more of.

One of the ways we are doing this at NIDRR and other government agencies is through the Interagency Committee on Disability Research. At the subcommittee level, we are strengthening the Disability Statistics Subcommittee, which has extraordinary leadership in Paul Placek and in Sean Sweeney. We have established a subcommittee on technology, which has a tremendous amount of energy, and it is co-chaired by the National Science Foundation and by NIDRR. We are establishing a subcommittee on medical rehabilitation, and I have every hope that there will be three agencies co-chairing that. Finally, we hope to have a special group on employment. I see the ICDR as one of the vehicles for creating collaboration among the various professional groups and disciplines and agencies of government.

I also see the work on the ICIDH as a way to collaborate, to create more of a bridge between the individual level of analysis and environment.

The guidelines related to the Americans with Disabilities Act and other laws, which have been developed with input from architecture and from builders and from engineers, need to be transformed so that they are useful within the environmental framework.

NIDRR does very much support CDC's work in surveillance. It helps to address one of the Office of Special Education and Rehabilitative Services and NIDRR's goals, to focus on the emerging universe of disability through trend analysis. The other

goal—and you will see it a great deal—OSERS is really taking the lead not only in the emerging universe but in areas of accessibility, and they are really moving in those areas, not only within the government, but also internationally, in the common agenda with Japan and the work with the European Union. So we really welcome the CDC initiative on the emerging universe.

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SUMMARY

MITCH LaPLANTE
University of California, San Francisco

The first Disability Statistics and Policy Forum addressed disability statistics policy generally, and asked the question: Should we continue to tinker around the edges and make incremental changes to disability surveys, or should we try to design something that gets more at what we need? People said that new surveys were too costly, that there was a lot that could be done incrementally.

I think this issue has arisen here again at this Forum. Lois Verbrugge said that there is a lot of data and plenty of analysis that can be done, and we can look at things a little differently in terms of environmental factors than we have done so far. I think that is true.

But when we are grappling with many of these issues related to disability and surveillance and interventions, I often feel that we need a whole army to evaluate disability in just one person. We have an interest in looking at communities—how they are structured and their environment. I think we still have a very large task ahead of us to do trend monitoring and surveillance of disability, and to be able to get our graphs around many of the factors that are related to this discipline.

The Behavioral Risk Factor Surveillance System is great for state estimates, and I hope that that can be improved. There may be new surveillance and monitoring efforts that come about as a result of CDC and other activities.

But one thing that I thought we might discuss a little bit more than we have is this: When we consider the National Long-Term Care Survey and when we see the declining proportion of elderly with IADL limitations—particularly those with limitations in traveling and preparing meals, which relatively declined the most—what does that mean?

If elderly people are more able to travel, how does that relate to the Americans with Disabilities Act? And how does that relate to airport accessibility and airlines actually helping people with disabilities to get from the gate to the plane and to get into the planes and to use the bathrooms in the planes?

There have been advancements in the environment due, no doubt, to that particular measure. When we look at things like preparing meals, shouldn't we be asking if elderly people are less limited in preparing meals, shouldn't we be asking about Meals on Wheels, programs for prepared meals that can be delivered to people? Or if people are making meals themselves, shouldn't we be asking questions about the process of making meals and the technology available? Are there microwave ovens that are now more prevalent, more affordable? Do elderly people have more of these? Are they using them to make meals, so that they can make meals more easily?

I think we have debated a lot about things we have learned from data that we have, but I think we also still have an obligation to try to make improvements for the future, so that we can answer why it is that disabilities are going down or maybe are not going down or maybe going up for certain populations. I am quite sure that the limitations that we have in national data are there, and we need to consider ways to reduce them.

Maybe we need to develop an environmental module, which would have to be validated and tested, based on survey respondents' ratings of the accessibility of their environments? That is one avenue that could be pursued. Maybe we have to make measurements on communities, and relate them to the communities in which the respondents have been sampled, comparing their composition and accessibility.

I think that these are questions that we are just beginning to realize are important, questions that we need to consider in future survey efforts.

I agree very much with Jamal Mazrui's point of view, which expresses the motivation for having a meeting like this. Yes, survey statisticians do need to talk to people with disabilities, and survey designers need to do that, as well. I think the interaction that we have had at this forum, between people with disabilities and the statisticians and analysts of various surveys and the policy people, is the way to make improvements in the future.

I will tell you frankly that the reason that I even mentioned telephones in the report that Mary Grace Kovar mentioned is that I got a question about how many people with disabilities don't have telephones in their households. I realized that it was an important question, and the next time I looked at this data, I analyzed the data in that way.

It is necessary to be reminded of the needs of people with disabilities and the disability community so that we can do better work in our surveys and in our analyses.

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